

# Report



Oslo –

Norway

**28<sup>th</sup>-30<sup>th</sup> October 2005**

## ***Ideology and Future Perspectives***

Our goal with EEXM is to create an open forum for exchange of new ideas, self-help experiences and future emphasis.

Norwegian Self-Help Forum  
Norwegian Directorate of Health and Social Services



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#### **Training Programs for Self-Help Groups to Increase the Key Factors for Successful Group Work.**

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Russian Federation:

#### **Role and Concept of Self-Help Groups in Russia: Self-Help Groups and Parents.**

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#### **Self-Help Groups in Developing Drug Effective and Treatment Strategies in Central and Eastern Europe.**

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Greece:

#### **How do we Communicate Self-Help in Greece?**

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Sweden:

#### **Communicating Self-Help in Western Sweden**

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Denmark:

#### **Self-Help Groups Interplaying with the Surrounding Society**

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How can an international self-help network be a driving force for the power of self-help in a health prevention perspective?

### **Driving Forces and Barriers in the Self-Help Arena.**

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United Kingdom:

#### **Participation in Cancer Self- Help Groups amongst Black and Ethnic Communities**

*Mr Mark Avis and Seeta Patel, University of Nottingham*

Norway:

**A Course of Studies in Self- Help Ideology and Methods**

*Manager Jan Ole Bolsø, Centre for Patient Information and Education*

Germany:

**Future Perspectives on Self-Help in Germany**

Scenario building and presentation of a network model.

Psychologist Jürgen Matzat, University of Giessen

# Programme

## Friday

- 1300 - 1530 **Welcome and Opening of the EExM for Self-Help 2005. Oslo City Hall**  
*Commissioner for Department of Welfare and Social Services - Margaret Eckbo*  
*Norwegian Self- Help Forum - Manager Solbjørg Talseth*
- 1600 - 1700 **Registration at the Soria Moria Hotel**
- 1700 - 1730 **Opening - Introduction EExMeeting for Self-Help - Goals and Emphasis.**  
*Norwegian Self- Help Forum – Manager Solbjørg Talseth*  
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- 1730 - 1750 **The Power of Self-Help and National Experiences.**  
For the individual, groups, organisations  
What is the “The National Plan for Self-Help” for Norway?  
*Norwegian Self -Help Forum*
- 1800 - 1815 **Performance by Norwegian singer Unni Wilhelmsen**
- 1815 - 1845 **The Power of Self-Help and International Experiences**  
*Psychologist Jürgen Matzat, University of Giessen*
- 2000 - **Dinner**

## Saturday

- 0900 - 0945 **Self-Help - Experiences from the Self-Help Arena.**  
Abstract sessions (15 minutes)
- Lithuania: **Successes and Challenges of Self-Help in Lithuania, 2001-2005.**  
*Chairwoman Violeta Ivinskiene and Ilona Buozyte*
- Switzerland: **Training Programs for Self-Help Groups to Increase the Key Factors for Successful Group Work.**  
*Ruth Herzog Diem, Team developer /Coach/ Body psychotherapist*
- Russian Federation: **Role and Concept of Self-Help Groups in Russia: Self-Help Groups and Parents.**  
*Olga Fedorova, Deputy Director for Science*
- 0950 - 1005 Abstract sessions continue (15 minutes)
- France: **Self-Help Groups in Developing Drug Effective and Treatment Strategies in Central and Eastern Europe.**  
*Dr Thomas Kattau, Principal Administrator of the Pompidou Group*
- 1005 - 1020 **Plenum: Questions and answers**
- 1030 - 1120 **Work shop I - group sessions** (see page 4)  
Are there fundamental values for self-help groups?  
*Sociologist Anne Diemer, Denmark*
- 1130 - 1200 **Group presentations**
- 1200 - 1430 **Lunch and social programme**

- 1430 - 1530 **How do we Communicate Self-Help in our Country?**  
Abstract sessions (15 minutes):
- Introduction by The Norwegian Self-help Forum*
- Belgium: **How do we Communicate Self-Help in Belgium?**  
Mr Peter Gielen
- Greece: **How do we Communicate Self-Help in Greece?**  
*Psychologist/Co-coordinators of Self-help Promoting Programme:  
Lainas Sotiris and Fragiadakis Kostas*
- Sweden: **Communicating Self-Help in Western Sweden**  
*Bjarne Rehnberg, frivilligsamordnare, Primärvården*
- Denmark: **Self-Help Groups Interplaying with the Surrounding Society**  
Sociologist Anne Diemer - Manager of Volunteer Centre/Self-help project.
- 1530 - 1550 **Coffee break.**
- 1550 - 1630 **Work shop II - group sessions** (see page 4)  
How can an international self-help network be a driving force for the power of self-help in a health prevention perspective?
- 1635 - 1705 **Group presentations**
- 1710 - 1740 **Driving Forces and Barriers in the Self-Help Arena.**  
Norwegian Self-help Forum - *Plenum discussion*
- 1900 - **Social** (Dinner at 19.30)

## Sunday

- 0900 - 0950 **Future Perspectives for Self-Help.**  
Abstract sessions (15 minutes).
- United Kingdom: **Participation in Cancer Self-Help Groups amongst Black and Ethnic Communities**  
*Mr Mark Avis and Seeta Patel, University of Nottingham*
- Norway: **A Course of Studies in Self-Help Ideology and Methods**  
*Manager Jan Ole Bolsø, Centre for Patient Information and Education*
- Germany: **Future Perspectives on Self-Help in Germany**  
Scenario Building and Presentation of a Network Model.  
Psychologist Jürgen Matzat, University of Giessen
- 1000 - 1050 **Future Perspectives and European Network for Self-Help**  
Scenario Building and Presentation of a Network Model.
- 1100 - 1150 **Closing session – Plenum discussion and summary**

## Introduction

The aim of the European Expert Meeting (EExM) is to create an open forum for the exchange of new ideas, to share self-help experiences and to discuss future emphases. International relationships and networks are important when developing the field of self-help. During the conference we have been introduced to a variety of self-help activities and experiences from different countries. We shall give a brief summary of some of the experiences that we were presented with:

From the Norwegian Directorate of Health and Social Affairs we had a presentation of the Norwegian mental health reform 1998-2008 which regards self-help as a part of public health activity and as an important supplement or alternative to professional help. The Norwegian health authorities' emphasis on self-help is expressed in the National Self-Help Plan of 2005 and in the funding of a nodal point for self-help in Norway in the years to come. The nodal point for self-help will carry out extensive work on information and dissemination, develop knowledge on self-help, its methods and usefulness, and also act as a coordinator in a self-help network. The nodal point of self-help will also work to strengthen the self-help activities through the funding of research and knowledge development.

The Norwegian Self-Help Forum presented experiences of self-help initiatives that have been carried out in a wide range of different arenas. The Forum defines self-help in this way:

*Self-help is to get hold of one's own possibilities, discover one's own resources, assume responsibility for one's own life and steer it in the desired direction. Self-help is to set in motion a process leading from passive recipient to active participant in one's own life.*

The self-help concept, its methods and ideology have been introduced to a range of different patient organisations in Norway. This has resulted in the establishment of self-help groups for people who want to give up smoking, struggle with serious overweight, live with traffic injuries, etc. It is also interesting that the Self-Help Forum has taken initiatives aimed towards health professionals and has arranged workshops on how to use individual resources in their professional activities. The Norwegian Self-Help Forum has also for several years worked intensively with the National Plan for Self-Help, and now has the task of implementing the plan and establishing the nodal point of self-help in Norway as mentioned above.

Jürgen Matzat gave us an overview of the history of self-help in different countries in Europe. He showed us how the development and expansion of self-help ideologies correspond with social, political and cultural conditions in the modern world.

The self-help experiences presented from Lithuania came from the organisation Parents in Partnership. Parents in Partnership is organising the parents, siblings and other relatives of drug addicts. The goal of the organisation is personal, organisational and political: They promote self-help and offer support to persons who are in a close relationship with drug addicts. They also try to develop a network of self-help groups in Lithuania and work to awaken public opinion about drug addicts and their situation.

From Switzerland we heard of experiences from a training program with the National Clearinghouse for Self-help groups directed at increasing the key factors for successful group work. Five factors were shown to be crucial to success in group work:

- The groups need to focus on mutual support.
- The groups need to talk about the goals of the individual, as well as the goals for the group as a whole.
- The groups need to decide the issue of leadership.
- The groups need to decide the group structure.
- The groups need to find answers to relationship building.

The project team emphasised that above everything the power of self-help groups is *within* the group. This is the difference between a therapeutic group run by professionals and a self-help group in which members receive and give help to each other. It is crucial for self-help groups to preserve their independence and individual responsibility with regards to professionals as well as to any group facilitator.

From the Russian Federation we learned that self-help groups are oriented towards meeting the needs of parents of different categories: parents of disabled children, single parents, parents of drug addicts, etc. There are various approaches and there is no clear definition of concepts. Self-help groups and support groups are often regarded as the same. Professionals seem to play an important role in the work of self-help groups for parents of drug addicts. It is important to encourage Russian experts working with self-help groups to participate in international self-help networks. This should include the participation in training activities as well as the development of new online and Internet resources.

Self-help groups as a concept, as a method or as a technique is quite difficult to communicate in Flanders to day, our speaker from Belgium explained. Twenty years ago it was much easier. The difference between self-help and self care, self diagnosis, self management etc. is vague in Belgium. Many associations prefer to call themselves a patient association, league or working group. The double connotation of the word self-help makes it difficult to use. The work of self-help clearinghouses, in facilitating and supporting self-help groups, is vague for most people and such activities are given little attention in the media. It is even difficult to advertise the starting up of self-help groups. This makes existing self-help associations quite creative in their attempts to receive attention from the media.

Self-help groups need allies and assistance, and it is important to create and reproduce a favourable climate for self-help. In Flanders they do this by ensuring that the Flemish self-help groups perform a good job and are prepared for present day challenges through offering information, education, customer tailored advice and support. They also work on a sound public relations policy, instead of conducting promotional activities.

Self-help in Greece is at an initial stage and is not particularly widespread. There is no national policy or planning in the self-help field. Neither is there a clear definition of what a self-help group is. A Self-Help Promoting Program is being implemented under the supervision of the Social and Clinical Psychology Section of the School of Psychology, Aristotle University of Thessalonica. The aims of the program are first and foremost to:

- promote a self-help approach to people with substance abuse and other psychosocial problems,
- sensitize and train health professionals regarding self-help and its applications,
- conduct research on the applications of self-help when confronting psychosocial problems.

The Self-Help Promoting Program meets with a lot of difficulties; lack of public policy on the issue, lack of knowledge among health professionals, lack of registration of self-help initiatives and lack of networking among the self-help groups. In the years to come it will be essential to work with these challenges.

Self-help groups in western Sweden take the form of discussion groups. The groups normally sit around a table and discuss a problem that the group members have in common. The groups are independent, they don't have any leader, and they don't belong to any organisation, party or church. The self-help groups are using much of the same method as Alcoholic Anonymous, AA. They experience that it is not easy to get Swedish people engaged in self-help activities because:

- people have access to all kind of social services,
- people prefer educated helpers or experts,
- It is easier to start a self-help group in the city than in more rural areas.

Still, despite the lack of national and local financial and ideological support, different kinds of self-help activities are growing in Sweden

In Denmark they have experienced that bridges have been built from self-help work to other parts of the volunteer world, to the professional therapeutic world, to the municipal and state institutions and to the surrounding society. The self-help activities in Denmark are closely linked to local volunteer centres. The cooperation with other volunteers and the professional world has resulted in more self-help groups and new types of groups. On the other hand the self-help groups lead more volunteers to other volunteer groups and at the same time create new methods within the professional therapeutic world. They are now taking initiatives with Danish health authorities to get financial support to expand the self-help work in Denmark, along the lines of the Norwegian model.

In England a research project was carried out in Nottingham to find reasons why people from different ethnic groups are not involved in self-help activities. The researchers found several circumstances that seemed to hinder people from participating and found that self-help was perceived in very different ways. Gender, generation, language, fears concerning confidentiality, problems with identifying and belonging to the group, lack of shared experiences are just some of the difficulties that confront self-help activities in a multicultural context. At the same time the study shows how crucial it is to create a sense of togetherness, look for shared experiences and acknowledge and respect differences in self-help activities.

In their aim to handle different types of chronic diseases, the Centre for Patient Information and Education in Norway, KPI, sees self-help as a valuable approach and tool for different categories of patients. At the same time KPI realises that if the patients are going to be introduced to self-help ideology and its methods, it is necessary that health professionals understand and make use of these methods. This also means they have to be door openers and promote this work. If self-help is to be accepted by the health service, the health service itself must see the value of it. One important step in the right direction will be to implement courses on self-help as a part of the education of different kinds of health professions. Courses in self-help must be based on research and research-based knowledge if it is to be a part of the education system at university college level. The fact that health authorities and university colleges become involved will not result in an instrumentalisation of self-help. The ideology is so solidly anchored in the real life world that the system will not be able to annex the experience based knowledge.

Through these presentations of different self-help activities we see many similarities as well as differences. For the most we see different self-help activities in different countries. Some such activities have been going on for decades and incorporate many different fields. Other countries have just started working and the philosophy of self-help is still not fully acknowledged and is only being applied to a few fields such as drug abuse. Furthermore, because there are differences concerning the involvement of national and local health authorities, it is economic and /or more practical assistance that is crucial when it comes to the conditions and frameworks self-help initiatives are given. The different presentations show us that self-help can be described and understood in many different ways. One main difference seems to be whether professional health care workers are involved or not. What they all have in common is that people with a problem are helping others with the same problem. It is mutual help. Self-help helps people to get mobilized and teaches them how to deal with and cope with their own problems and life. Self-help contributes to empowerment.

One of the main goals in this conference has been to build international networks. If you look up the term *network* in a dictionary to find a definition you will find, among others, the following: "A network is an extended group of people with similar interests or concerns who interact and remain in informal contact for mutual assistance or support." That has been the main goal of this conference: To create and affirm networks between people from different countries who in one way or another are engaged in self-help activities. Through the sharing of our different approaches and experiences from the self-help field, we gain mutual assistance and support. That is in accordance with the ethos of self-help ideology itself!

***Oslo, May 2006***  
***The Norwegian Self-help Forum***

## **Opening - Introduction EEx Meeting for Self-Help - Goals and Emphasis.**

*Norwegian Self-Help Forum – Manager Solbjørg Talseth*

I am pleased to welcome you to the beautiful Soria Moria Hotel. We are now outside the center of Oslo, but close to the famous ski jump called Holmenkollen, which was the arena for the Olympics in Oslo in 1952. Did you see it when you drove past?

My name is Solbjørg Talseth, as I told you earlier today at the City Hall, and I am the manager of the Norwegian Forum for Self-Help. This weekend The Norwegian Forum for Self-Help is co-hosting this meeting together with the Ministry of Health and Social Affairs.

Norwegian health authorities are interested in developing the potential of self-Help. In the mental and psychological health work, where several angles of approach need to be applied simultaneously, the self-Help effort is regarded to be an important mastering tool.

International relations and network will be an important asset when working toward this goal.

I'm so pleased to see both old friends and colleagues. This is the sixth European Expert meeting I'm attending, and I am also pleased to welcome new countries and colleagues; The Russian federation, Lithuania, France and Greece – and also some new Norwegian friends - and of course we wish them all especially welcome!

I regard this meeting as OUR meeting. Even though you have been invited to Norway, this doesn't mean that we will provide everything for you.

In other words, this Expert meeting is truly an open forum for exchanging new ideas, self-help experiences and future emphasis. And we can only do this together by participating and sharing.

The social interaction outside this room is also very important. Tomorrow's plans originally included sightseeing after lunch, but we decided to cancel it, instead we are giving you the opportunity to spend some time walking and talking.

During this weekend we hope to get to know each other, build new, and strengthen old networks. We also hope that we will all be familiar with the variety of experiences in the self-help field in our different countries, and when we leave each other on Sunday I hope we have managed to mix all of our thoughts, experiences and goals into our already existing network, a network that will continue to exist and be alive also in-between these meetings.

When we split up on Sunday after lunch I hope and wish that we will be more educated, wiser and even more enthusiastic about the enormous power of self-help – both locally, and in an European perspective.

We have an extensive program covering many topics. We have chosen to do so because it will give us an idea of what the variety of self help represents and what is ongoing in the different countries.

I want to thank you all for a wonderful contribution to the program.

Well, I'll ask you to be open-minded and flexible about the program, there might be some minor changes as we go along.

Unfortunately, Elzbieta Bobiatynska from Poland had to cancel yesterday due to unexpected circumstances in her family. She was very sorry and gives her regards to everyone.

I do hope you will enjoy your stay here at Soria Moria and that we after this meeting are positioned to take further important steps into the field of self-help.

Last, but not least, I would like to make special thanks to the Ministry of Health and Social Affairs. Not only are they co-hosting this Expert meeting, they have also made this whole meeting possible through founding.

Thank you.

I would now like to welcome The Norwegian Ministry of Health and Social Affairs represented by project director Mari Trommald  
The floor is yours!!!

## **Opening - Introduction EEx Meeting for Self-Help - Goals and emphasis.**

*Norwegian Directorate of Health and Social Affairs*

*Mari Trommald MD, PhD*

### **Long traditions for self-help**

1935: Alcoholic Anonymous established in Norway

1985: Self-help work starts to flourish

1993: Report No. 16 from the Ministry of Health and Social Affairs: "Don't let grass grow between neighbours"

*"Self-help groups consist of people who have a common problem and common experiences, who join forces to achieve personal development.*

*Self-help groups offer no therapy or treatment, but are built on mutual support between equal participants.*

*Self-help groups can be both an alternative to and a supplement to public services and are therefore centrally placed in the interaction between public and private services.*

*Self-help groups are increasing in numbers and are applied to ever increasing areas"*

1998: Norwegian Self-Help Forum established

2005: Self-help groups exist for a number of patient groups, relatives, people who feel discriminated, people who experience life crisis

### **October 20th 2005: Tidsskrift for Norsk Lægeforening 2005; 125**

2 year follow-up study on self help groups in drug treatment: 81% drug free in the intervention group, 26% drug free in the regular treatment group.

### **Mental health reform 1998-2008: White paper (1997) - conclusions:**

- Inadequate preventive measures
- Inadequate municipal services
- Poor access to specialized health care
- Hospital stays without continuity and follow-up
- Hospital discharges were not sufficiently planned
- Poor follow-up systems and routines after discharge

### **Conclusion by Parliament:**

The patients are not receiving the help and services they need, health professionals and staff do not feel they are doing a good enough job, and the authorities are not able to supply the public with adequate and well-functioning services. (St.meld nr 25 (1996-97).

### **National mental health program/reform 1999 - 2008**

*Overall goal: create adequate, coherent and well functioning services on all levels for people suffering from mental illness.*

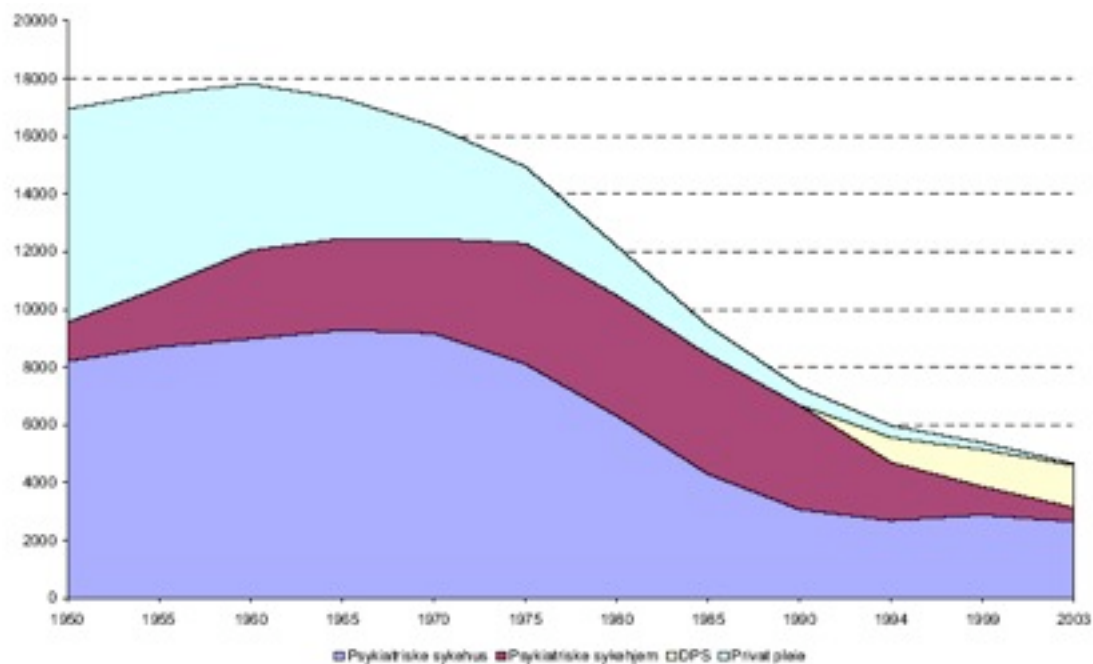
### **Change of attitude**

#### **Respect for the user's experience**

- Empowerment
- User participation
- Strengthen the ability for patients to take part in their own process of change
- Access to services when needed

### Essential features of the program

- A phasing-out period regarding traditional psychiatric services and mental institutions
- A reorganization of mental health services
- Building up and strengthening municipal and local community services to people suffering from mental disorders
- Participation of service users' organization and other mental health advocacy groups on all levels of government work regarding mental health issues
- Special focus on children and adolescents with mental problems and disorders

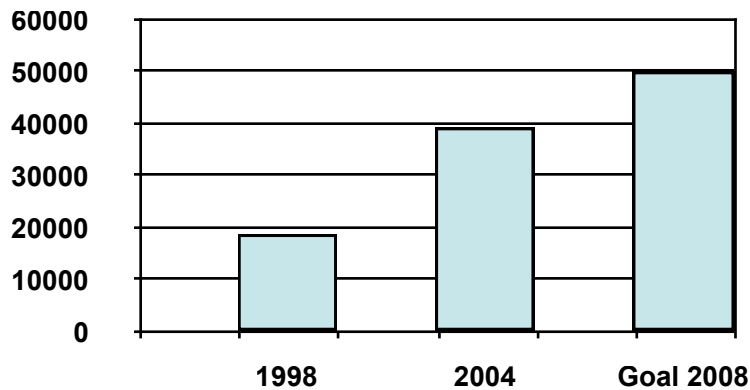


Figur 2.1 Antall pasienter i ulike institusjonstyper fra 1950 til 2003. Middelbelegg.

### Specialized health services

- Mental hospitals with specialized functions
- Private practicing psychiatrists and psychologists
- Community mental health centers (CMHC);
  - Objective: collaborates with the hospitals and the primary health care and municipal services
  - Population coverage pr unit: 30 000 – 50 000
  - Area coverage: 86% of the country (2003)
  - Services and units:
    - Outpatient clinic and services
    - Day Treatment Clinic
    - Crisis Resolution and Home Treatment Teams
    - Inpatient Units/Services

## Achievements: 19 000 more children are treated



## Primary health care services and mental health

Target areas;

- Satisfactory housing and accommodation with adequate assistance if necessary
- Promotion of participation in labor market/ occupational activities for people with mental illness
- Activities targeting the need for social contact, feeling of connectedness and integration
- Adequate and well-functioning health and social services along with preventive measures

## Essential features of the program

- Information strategies and educational campaigns targeting children and adolescents, service users and providers, work places and the general public
- Stimulate education and research in the field of mental health
- Increase training and recruitment efforts regarding qualified professionals and staff working with people suffering from ill mental health

## Challenges

- Collaboration
- Accessibility
- Professional content
- Efficiency
- Communication
- Documentation

## “Prescription for a Healthier Norway”

*“The Government does not view the concentration on self-help as relieving public agencies of their obligation to provide help, but as an important supplement or alternative to professional help”*

Self-help being a part of public health work

## National Self-Help Plan

- "Establish a nodal point to carry out extensive information and dissemination work, knowledge development and to act as coordinator in a self help network"
- "Research, knowledge development and dissemination"
- "Grant scheme"
- "Annual national conferences"
- "International conference"

**Self-help is a natural resource.**

**We want to learn how to utilize the self-power of the individual when life is difficult.**

## **The Power of Self-Help and National Experiences.**

For individual, groups, organisations  
What is the Norwegian “National Plan for Self-Help”?

### *Norwegian Self-Help Forum*

Norway has long traditions of self-help. Alcoholics Anonymous was established in Norway as early as 1935, and during the mid-80s the self-help work started to flourish, at exactly the same time as in the rest of Europe. Which is an interesting phenomenon in itself?

As a result of the establishment of the foundation Norwegian Self-Help Forum in 1998, development work has been carried out in recent years in the area of self-help. At present, self-help groups exist for a number of patient groups, relatives, people who feel discriminated and people who experience life crises such as bereavement, break-up of relationships and unemployment.

However, the self-help work continues to be fragmented and is without a network, and the lack of systematic concentration puts self-help out of reach as a tool for those who may need it. In many contexts self-help is a tool both for users and helpers, but our knowledge about this is still inadequate. There is also insufficient systematic research being carried out into self-help methodology and the effects of the self-help effort.

Research conducted in this field (Sorg og omsorg, (Grief and Care), University of Bergen and Oslo University College) concludes that there is a requirement for a national resource centre and also a need for structure, guidance and a framework to enable as many as possible to benefit from understanding self-help.

## **What is self-help?**

The Norwegian Self-Help Forum looks at self-help as the use of resources within each individual. Self-help is aimed at empowerment and user participation and represents work that strengthens the individual's ability and opportunity to take part in his or her own process of change.

This way of looking at self-help, is reflected in The National Plan for Self-Help:  
*“In a public health perspective, mental and psychological health is a central element and is closely connected with such terms as mastery, the ability to change, and quality of life. It concerns the personal resources of individuals in day-to-day life, our ability to resist psychological and physiological trauma, and our ability to manage our own lives.”* (The National Plan for self-help, pg 5)

## **Self-help**

Self-help is a concept that is used in various contexts and that is at present diffuse and abstract for many. However, organizations and experts appear to agree on the following points:

- Self-help is to take active responsibility for one's own life situation.
- Self-help is run on the initiative of the people in question, and self-help groups are run by people with a common problem.
- Self-help can be a supplement and an alternative to public mental health and other services.

The elements in Self-help as a tool:

- Knowledge
- Consciousness

- Mastering
- Adoption

Already in 1993, Report No. 16 from the Ministry of Health and Social Affairs to the Norwegian parliament entitled: "Don't let the grass grow between neighbors", which was a report on voluntary work, described self-help work as part of the political and governmental effort:

We quote from the Report:

"Self-help groups consist of people who have a common problem and common experiences, which join forces to achieve personal development. Self-help groups offer no therapy or treatment, but are built on mutual support between equal participants. Self-help groups can be both an alternative and a supplement to public services and are therefore centrally placed in the interaction between public and private services. Self-help groups are increasing in numbers and are applied to ever increasing areas."

One possible definition:

*"Self-help is to get hold of one's **own possibilities**, discover one's own resources, **assume responsibility for one's own life** and steer it in the desired direction. Self-help is to set **in motion a process** leading from passive recipient to active participant in one's own life".* (National Plan for Self-Help Page7)

#### **National experiences on different arenas:**

There are very few clear limitations with regard to which groups can benefit from self-help.

- **Norwegian Cancer Association**  
Smoke ending groups for women entitled: "It's time to be independent"  
The tool is self-help.  
Approx. 65% stopped smoking after 6 months
- **NHFS: Norwegian Health Promoting Hospitals**  
Workshop: "How to exploit individual resources in professional life"  
Self-help for professionals in their work environment.
- **Overweight treatment: "On My Way to Equilibrium"**  
In collaboration with Helse øst (Regional health institution)  
Physical health – Mental health – Self-help tool and groups.
- **Anxiety Ring Norway – A Self-Help Organization.**  
Represents experiences from an organization in the voluntary sector.
- **The Norwegian Association of Traffic Victims**  
Represents experiences from an organization in the voluntary sector.  
The organization has integrated self-help groups as a tool for life changing processes.  
Self-help as a natural offer to their members together with expertise.  
Implementation building a nation wide network of self-help coordinators.
- **Organization for Relatives of Psychiatric Patients (LPP)**  
*"Attending the group gave us a process that strengthens our lives and personalities..... thus also strengthening our sister or brother suffering from psychiatric diseases."*

- **Association for People with Spinal Core Problems**  
The organization has integrated self-help groups as a tool for life changing processes.  
"Participation in the group has undoubtedly increased our quality of life"  
A group of 7 women suffering of spinal core problems. Two participants got back to regular work.
- **1999-2005 "From Passive Recipient to Active Participant.**  
Establishing a local clearinghouse for self-help and voluntary work in Oslo. Financed by Oslo municipality. The first (and only) centre in Norway.  
Link Oslo is a neutral arena for self-help empowerment.  
For organizations, volunteer organizations and others in Oslo.
- **Self-Help Networks:**
  - o National Volunteer Centers (Frivillighetssentraler)
  - o National Patient Learning Centers (Lærings- og mestringssentre)
- **Self-Help in Education**  
Tools for self-help, user experiences and communication for professionals.  
Oslo University College, Oslo Municipality among others.

Self-help is aimed at self-mastery and user participation. The basic principles of self-help work - independence and the ability to master one's own life - can result in an improved quality of life and can increase the opportunities of the individual to partake in the community.

In the future self-help on the Internet is looked upon as a new arena.

### **National Plan for Self-Help**

In order to strengthen the national self-help work and make it more accessible in the field of mental health, The Norwegian Self-Help Forum was in 2001 tasked by the Ministry of Health and Social Affairs with developing a draft plan to strengthen and further develop the self-help work.

The self-help plan was first introduced in Report No.16 to the Norwegian Parliament 2002/2003 entitled "Prescription for a Healthier Norway", which is referred to as the "Public Health Report", and which is part of the work to implement the Escalation Plan for Mental Health.

We quote:

*"The Government does not view the concentration on self-help as relieving public agencies of their obligation to provide help, but as an important supplement or alternative to professional help."*

In "Folkehelsemeldingen" (The Public Health Report) (Report No.16 to the Norwegian Parliament, 2002/2003), the following objectives have been set for a national concentration on the self-help work:

*"The overriding objective of the national plan is to strengthen the self-help work. This endeavor aims to ensure that previous experience from self-help-related work and projects is brought into use and further developed, and to strengthen the self-help work in existing networks. At an overarching level, the plan is intended to help build up and pave the way for structures that ensure the self-help work is strengthened and*

*continued after 2006. The objective is to make self-help as a method available to more people, to promote systematic method development and knowledge about self-help, and to be instrumental in ensuring that the self-help tool can be used in mental and psychological health work, both by the users and the helpers/professionals.” (p. 58)*

The National Plan for Self-Help is presented in "St meld 16, 2002-03" **The Public Health Report**

We look at self-help as development work intended to gather all experience and knowledge gained in the self-help work and make it available to the general public.

Via the plan a development effort will be carried out with regard both to content of the self-help and methods of organizing the work.

**Self-help is aligned with self-mastery** and user involvement. The self-help effort represents initiatives that are aimed at strengthening the ability and opportunity of individuals to partake in their own process of change.

### **National Plan for Self-Help - Five Initiatives – (Page 14)**

In the "Public Health Report" (Report no.16 to the Norwegian Parliament, 2002/2003) **five initiatives** have been listed:

- Establish a **nodal point** to carry out extensive information and dissemination work, knowledge development and to act as coordinator in a self-help network.
- **Strengthen the self-help work** through funds for **research** and knowledge development.
- Organize an **international conference in 2005** aimed at expanding knowledge about self-help.

The Government wants to establish a nodal point as it sees the need to strengthen the self-help work in relation to mental health. This is basically intended as a time-limited project but, if the evaluation at the end of 2007 so indicates, it will be assessed whether the nodal point should be established with a more long-term time horizon. The nodal point is intended to help gather, systematize and disseminate the knowledge that exists, and to emphasize model development around self-help and mental health. Through network effort and dissemination activities the objective is to create synergy effects across different environments.

### **National Plan for Self-Help - HOW?**

- 1. A nodal point - Reference group**
  - Research
  - Competence development
  - Politics
  - Coordinators Network
  - Information
- 2. Networking through established networks**
  - Professionals
    - Universities

- Professional **unions**
  - Volunteer organizations
  - Health institutions
    - Hospitals
    - Public advisors etc
  - Public institutions
- 3. Create synergies and develop established network**  
 National nodal point for self-help  
 Escalation plan For Mental Health  
 Professionals - Health institutions - Public sector  
 Volunteer organizations - Volunteer centers
- 4. Operational work Implement Self-help in Norwegian communities**

### Challenges

As we know that the self-help work is dependent on continuous development and motion, and that the resource underpinning it is always the self-power of the individual, we also see a number of dilemmas in state-sponsored involvement in self-help:

1. How to avoid self-help from becoming stigmatized as a therapy offered by the public health service?
2. How to avoid self-help from becoming a cost-effective substitute for the State's development of good therapeutic services?
3. How to prevent the State from inhibiting natural growth?

How can the State help create the necessary arenas, framework and good growth conditions to ensure that the relational space represented by the self-help groups contributes to the generation of health benefits both for individuals and for society as a whole? This is a challenge we need to take seriously.

### Conclusion:

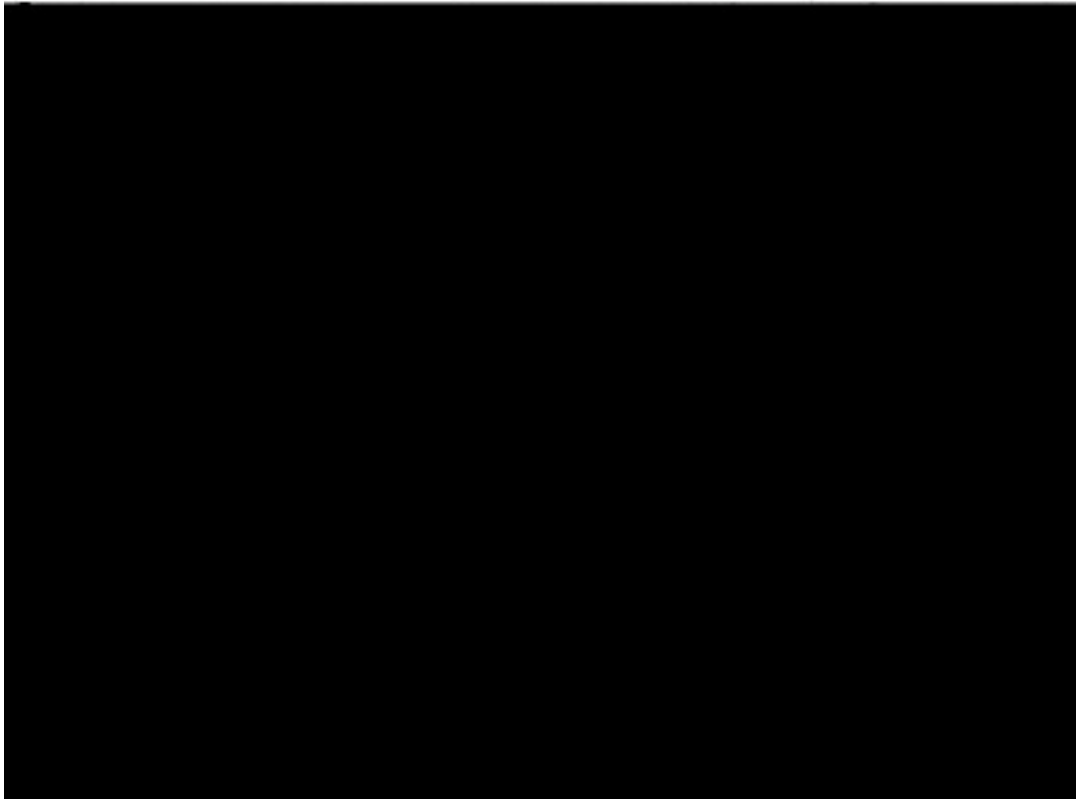
Successful health work depends on the ability and willingness to include intrinsic human resources as an essential ally. In this context we view self-help as a natural resource that we want to know more about and learn how to utilize the self-power of the individual when life is difficult. We are both proud and pleased that Norway is on the threshold of integrating self-help as an important part of the country's health and social work, but also as an important part of the country's health understanding.

Therefore, the challenge is to help ensure that the various players become active participants in the development of self-help work and in highlighting self-help as a tool, both for users and helpers.

The National Plan for Self-Help will promote both practice and research, and will in this way contribute to further development of self-help methods, both in practical self-help and in research.



**The Power of Self-Help and International Experiences**  
*Psychologist Jürgen Matzat, University of Giessen*



**SELF HELP IN EUROPE**

- Historically non-simultaneous
- System of government  
(federal / central, "Subsidiaritätsprinzip")
- National care systems  
(public, private, "third sector", charity, non-profit)
- National cultures and traditions  
(e.g. temperament, family structures, religiousness)

**COMMON CONDITIONS**

- Change in the spectrum of diseases  
from acute and infectious to chronic and psychosocial
- Disintegration of social networks  
e.g.: family  
neighborhood  
church (parish)  
party, union  
clubs, associations  
(cf. Robert Putnam: "Bowling Alone")

**Loneliness and isolation are RISK-FACTORS!!!**

Attachment, belonging, and sense of coherence are BUFFERS against stress

- Changes in value systems (after 1968 / 1989)  
social movements (women-, peace-, environment-)  
democratization, participation, empowerment,  
self-determination, self-assurance, self-responsibility, ....
- Education system, information technologies

### **SOME MILESTONES OF SELF HELP**

1935	AA (Bob and Bill meet in Akron / Ohio)
1968 (!)	Federal Working Group Aid for the Handicapped (BAGH) founded in Germany
1970s and 80s	Self help organizations of handicapped / chronically ill people mushroom in (central) Europe
1976/77	First textbooks on self help groups in USA by KATZ & BENDER, CAPLAN & KILLILEA, GARTNER & RIESMAN
1978/81	and in Germany by MOELLER
1977/79	First major research projects on self help groups in Germany (Giessen, Hamburg, Heidelberg). Further research in Belgium, England, Denmark, Norway. => Action research as an important resource for self help support and promotion (!)
1980s	Courses on self help at the IUC in Dubrovnik, sponsored by WHO-Euro
1980s	WHO expert workshops, on self help groups in Höhr-Grenzhausen (Germany) and in Leuven (Belgium)
1982	Recommendations by an expert task force of WHO-Euro to promote the establishment of "self help clearinghouses" (Selbsthilfe-Kontaktstellen) on local, regional, and national level
1983	"International Information Centre on Self help and Health" (I.S.S.), sponsored by WHO, in Hamburg, and since 1985 in Leuven
1984	First "Nationale Kontaktstelle" (NAKOS) in Berlin (other centers in Leuven, Barcelona, London, Odense, Tel Aviv, Vienna, Basel and Oslo)
1987	Government's programme of demonstration models on self help centers (Kontaktstellen) in Germany, later in England and Denmark
1991	First European Expert Meeting on self help groups in Frankfurt (since then bi-annually in Kolding, Klagenfurt, Bruges, Jerusalem, Budapest, Zurich, and Oslo)
2000	Statutory health insurances under public law in Germany are legally obliged to support self help groups, self help organizations, and self help Kontaktstellen (§ 20,4 SGB V)

2004

Patients' representatives and self helpers are involved in the "Joint Committee", the highest decision-making body of Germany's health system. Other countries will follow?

## Self Help - Experiences from the Self Help Arena.

Lithuania

### **Successes and Challenges of Self Help in Lithuania, 2001-2005.**

*Chairwoman Violeta Ivinskiene and Ilona Buozyte*

Public organisation, "Tėvų partnerystė" (Parents in partnership)

We are presenting the Lithuanian public organisation "TĖVŲ PARTNERYSTĖ" (Parents in Partnership). Our organization is consolidating parents, siblings, other significant relatives or family members of drug addicts.

The Norwegian Ministry of Foreign Affairs devoted much attention to self help initiatives in Lithuania, financing the project "Parents in Partnership", implemented with Vilnius and Klaipėda parents self help groups during 2001-2005 years.

A result of the project - establishment of our organisation last year .

We would like to talk about what is very important to us and makes us worry:

- our organisation is working only for one year, but activity of self help is not new in Lithuania
- inspite the growing of statistic figures of the registered drug addicts in Lithuania, (nobody knows the real figure of unregistered), very few people are joining our self help groups
- when analysing the causes, we find the same processes of changes as it has happened in other countries
- till now we had not enough means to split the information about us in the society and to become visible

Significant changes of state and social life took place in Lithuania after re-establishment of the independent state in 1990

- the "iron curtain" and censorship have kept Lithuania separate from the rest of the world for many years
- it seemed that neither narcomania nor prostitution or other social problems have touched us
- the borders of Independent Lithuania became open and it caused more threats for society: contraband of narcotics and as consequences
  - narcomania, crimes and violence, adiction and health problems
- the Lithuanian State Policy was not aimed to solve these problems
- society was not prepared to solve the problems too: during 50 years of Soviet occupation it was forced to think that decision-making is a right of authorities and the ruling party, thus people themselves cannot change or influence anything
- the Trade Unions lost their true meaning too, therefore now it is still very difficult to change mentality of the people
- new political situation caused great changes of social and economical life, as f.e. broken bonds and differentiation of society
- many people are expecting assistance from the state institutions but often are lost lonely to cope with the problems themselves
- there are no traditions of neighborhood communities or non-governmental organisations in Lithuania
- movement of Self help in Lithuania is on the initial stage
- there are established only several social organisations for invalids or parents, whose children are ill with cancer, for persons ill with sowing sclerosis, some communities on faith basis, etc.
- a number of drug-addict persons in Lithuania is increasing, as well as the age of drug-addicts and simultaneously is increasing a number of families members, whose life is effected by this misfortune

- the problem of drug abuse is great and the number of Self help groups should grow, but we meet with difficulties recruiting new members to Self- help groups, because we have a deal with a very subtle question
- opinion of Lithuanian population is that a drug-addict brings a shame to his family
- using of drugs is illegal in our country so families of drug-addicts avoid publication of family problem, thinking it is very private
- they do not apply to state institutions for the treatment avoiding juridical consequences
- the greatest part of the candidates to our Self help groups are women, in the age about 50 and the age of their children drug-addicts is about 20-35 years, the drug usage time 5-10 and more years
- financial situation in families is very hard and also mothers often are divorced or widowed and they are afraid to lose their jobs due to drug addicts in their families
- private assistance is inaccessible financially, parents and relatives seek way - out from hopeless situation singly and a right information about self help does not reach them
- on the other hand, people coming to Self help groups at first seek and expect help for their children but not for themselves
- they do not understand that first they should learn themselves:
  - how to cope with a problem and live with a drug addict together
  - to recognize that the process of recovering requires a long time
- an approach to a problem of drug abuse is different even between family members: men are prone to disguise their feelings and, besides that, often the relations between fathers and their addicted children are broken so, we meet a difficult task to involve fathers into self help group activities

**The goals of our organisation "Parents in Partnership" are:**

- to join together parents and other persons which are in a near relationship with the family members - drug-addicts
- to promote self help and support to each other, participating in self help groups
- to learn how to live with the problem a normal life and enjoy it
- to teach other parents help themselves and rise the quality of their life
- to develop a network of Self help groups through all Lithuania
- to become visible and form a different public opinion to the drug-addicts and their families: it is necessary to solve this problem openly and form the understanding that drug-addicts first are very seriously ill persons, who need medical and psychological help as well as their families
- to help the society recognise, that it is the problem of society but not of the family
- try to become a lacked chain in Republic in the area of the Narcotic Control and Drug-addiction treatment as a special group having a great expertise in this field and a strong responsibility and interest to get visible positive results
- try to assist the Lithuanian government and the Ministry of the Health, establishing a new Program with a treatment system for drug-addicts
- we think that only together with doctors and lawyers, politicians and all society members we can expect to achieve visible changes in our society and decreasing of narcomany
- we expect that other participants will share their experience in the field of self help, especially in recruitment and we could learn a lot of useful information
- we are glad that our project for development of Self help groups network in Lithuania was affirmed and we will be funded by the Nordic Council of Ministers and partly by the Drug Control department of Lithuania
- we believe that our activities with financial support will be more fruitful and will show positive results in the future
- we are sure that all of us are responsible for the future of our children and wish to see them safe and sound



## Self-Help - Experiences from the Self-Help Arena.

Switzerland

### **Training Program of the Swiss National Clearing House (KOSCH) for Self-Help Groups to Increase the Key Factors of a Successful Group Work**

*Ruth Herzog Diem, Team developer /Coach/ Body psychotherapist*

7,4 Mio. inhabitants live on a surface of 41'000 km<sup>2</sup> - Switzerland is a small country where the first steps towards a professional promotion of self-help groups were made 25 years ago. For the last years the national foundation KOSCH (coordination of self-help groups in Switzerland) has been providing support to the 16 regional clearinghouses (Kontaktstellen). These are very small organizations with an equivalent of nine employees. There are about 2000 self-help groups and 200 self-help organizations which deal with 300 different topics (e.g. depression, anxiety, diabetes, cancer, chronique pain, parents in mourning, AA + EA-groups, sexually abused women).

A study published in 2004 shows that 90 % of the groups examined, work without long-term professional support, 84% deal with health problems und half of them are closed groups (up to 12 members) with regular meetings.

### **Framework of the project**

We are two professionals in charge of the workshops. As the project leader, I cooperate with a colleague from a regional clearinghouse. So far, we have had 3 half-day, 2 one-day and 2 two-day workshops. The project ist sponsored by a Swiss health insurance.

### **Goals**

- Promote network of sh-groups and –organizations
- Decrease isolation
- Minimalise dependence on professionals and sponsors
- Allow for new perception

In German, this project is titled „Denk quer-Werkstattgespräche“, which means: think across borders, share your group issues with other groups. One of the reasons our workshops last for one or two whole days is that we want to encourage the participants to be open for new views, because sh-groups are likely to go on with dead-end solutions. We want to point out that their issues can more easily be solved by considering the key factors of a successful group work.

### **Five key factors of successful group work**

In order to understand a problem in the sh-help group and to be able to get along with it, we have to face the group as a whole system and remember what self-help is all about. The group has to get involved in the basic issues. If these can be clarified by the **whole** group, the group gets more powerful.

#### *1. Focus on mutual support*

Why are sh-groups so successful? Because people who share the same issue help each other and learn from each other. Every group member is a „client“ as well as a „helper“. Everyone is responsible for him- or herself and basically for the group as a whole.

#### *2. Goals of the individuals and the group*

Although group members share the same problem, they are likely to have various needs and goals. Some want to get information, others want to talk about feelings and how to cope with the whole situation. It helps the group to talk about the individual needs in order to decide where to go with the group as a whole.

#### *3. Leadership*

On one hand, the sh-group has to decide who takes charge of the facilitator's role. Many groups are organized democratically without a leader, sharing the leader functions. Groups with one leader are usually more powerful when they discuss and decide together about goals and questions of group structure.

#### 4. *Group structure*

How often do the group meetings take place? How long last the sessions? How is the procedure of a meeting? How to deal with absences or people leaving the group? Is the group open to new individuals and how to integrate them?

#### 5. *Relationship building*

The whole group finds answers to the following questions: how to deal with non stop talkers or emotionally very burdened group members, how to deal with advice, what „listening“ means, how to cope with conflicts, etc.

### **Methods**

We provide the participants with theory on communication and group dynamics. By focussing on topical requests of the participants we make sure that every single problem is taken seriously. There are many possibilities to lead a self-help group effectively and it is not our role to prescribe how they should run their group. However, they are encouraged to increase the key factors for successful selfhelp-groupwork.

The participants have time to share their experiences in groups, as well as learn some elements of a resource- and solution based group work.

### **Participants**

So far, 100 individuals from 50 sh-groups and –organisations have participated, for instance patients of a genetic disease, rheumatic disease, lesbian mothers, parents of a child with epilepsy, women with celibate partners,. The participants are mainly group members with leader function running new or very experienced groups.

### **Frequent topics**

***Overworked leaders – passive members:*** there are different ways of managing a sh-group. The clearing-houses in Switzerland (the German ones too) encourage new groups to share the charge of the group. Most groups without support of a clearinghouse give the leadership role to one person. In these groups, the leaders feel responsible for everything, they are frequently overworked and complain about passive members.

***Common problem – different personal goals:*** to be in the same situation doesn't mean that everybody has the same requests and goals in the group. While Ann wants the group to give her some advice, Kate hates to be given advice. Diana wants to discuss how the problems with her psychotic son affects her marriage, while John is more interested in PR-work on the rights of relatives in the psychiatric field.

***Integration of new group members:*** many groups complain about new members, leaving the group after a short time or demanding too much attention. Or they even fail to find new members.

***Problematic of dominating and extremely overwhelmed individuals in the group:*** what to do with Howard who can't stop talking about how unfair his loved ones react towards him or Judith who goes on with her never ending laments.

### **Case study: a group of parents of hyperactive children**

Let me explore some of the topics mentioned above, with regard to one specific group: *the parents of hyperactive children*: the group is facilitated by an experienced group member. The typical agenda of the group includes discussions, guest speakers and activities.

*Their main issues are:*

- High fluctuation of members
- No commitment of new individuals
- High effort (facilitator) – little return

There is a question of reliability. New people joining the group for a very short time, just unload without any commitment for the group as a whole. However, the group allows them to do so as long as the group doesn't communicate its rules and expectations.

*What is the typical solution?*

The facilitator intensifies PR efforts, she increases her involvement. The complaints about the minimal engagement of the members, especially the new ones, continue.

*Allow new perceptions*

The participants are encouraged to connect the issues with all the elements of a functioning group. We point out that's impossible to build up a group when there are one or two new individuals constantly joining the group each meeting. In order for a group to function, trust and solid relationships are needed. There are various reasons why new people unload their problems and never come back after one or two meetings. It might be because they are just consumers, or they might feel uncomfortable being a newcomer in a long term group. The group is challenged to discuss what elements in the group may prevent integration of new individuals.

In this group of parents of hyperactive children there are three women who have belonged to the group since eight years. Their bond to the group is strong due to their friendships developed over the years. However, they don't really need this kind of group anymore. Their needs are not longer addressed by this sh-group because their child is grown up. The group has never mentioned when to come to an end or what could be an adequate new form of contact. Sometimes the group must evaluate the group itself. This helps to avoid taboos like „when it is time to leave“.

From time to time, the group has to make up its mind about the goals, the structure and the relationship building.

If the group makes up this kind of decisions as a whole,, the self- help elements in the group are effective and the facilitator is less burdened. In this group of parents of hyperactive children, the facilitator realises the following dynamic: the less the group works, the more responsibility she takes on. She carries the group. Therefore the more she is active, the less the group is.

Facilitating a group is not only a question of having the right tools, but also of attitude. What motivates the group leader to do this voluntary work? What does he or she get out of it? The training allows them to think about it and to share their feelings and reflections with self- helpers from various groups.

## **Summary**

100 self-helpers have attended our workshops so far. Due to the PR of this training, some organizations like breast cancer and parents in mourning, have applied for comparable training programs for their self-help groups.

The power of self-help groups is *within* the group. There has to be an obvious difference between a therapeutic group run by a professional and a self-help group in which members receive and give help to each other. It is one of the main goals of sh-groups to preserve either independence or self responsibility towards the professionals as well as to any group facilitator. The group enhances its power by overtaking facilitator-function.

This is the advantage of traditional and future power of self-help groups.

## **Self Help - Experiences from the Self Help Arena.**

Russian Federation:

### **Role and Concept of self help groups in Russia: Self help groups for parents and drugs**

*Olga Fedorova, Deputy Deputy Director for Science, Centre for Social Assistance to Children and Families, Ekaterinburg, Russian Federation*

At present time in Russia self help groups are oriented towards meeting the needs of parents of different categories: foster parents, parents of disabled children, single parents. Self help groups for parents of drug users are widely spread among such groups in Russia. Despite the fact that there are different self help groups for parents, the interest of specialists and people was turned namely upon self help groups for parents of drug users because of the significance of drug problems.

Self help groups for parents of drug users had seen their spread in Russia at the beginning of 1990s. At this moment Russian specialists are interested in improving the activities of self help groups because there is a decrease in motivation for work in such groups.

Once my Norwegian colleague asked me to set up a meeting with a facilitator of self help groups for parents of drug users in Yekaterinburg. This city ranks third in Russia and is an industrial and administrative centre. It is situated on the boarder between Europe and Asia. This situation is of particular importance both for Russia and other countries. The first question I wanted to clarify was what self help groups for parents of drug users had been in Yekaterinburg?

Certainly, I searched in the Internet first. At first sight, the situation looked positive: there were addresses and telephone numbers of such groups, but the information I found was 3-4 year old. What were my further steps to find the groups?

- Enquiry services (chargeable and free of charge)
- Drug and alcohol abuse clinics and psychiatric clinics
- Municipal institutions involved in prevention of addictions
- NGO's

There was information about such groups but I did not get specific information. I had an opportunity to visit a charity foundation where there was such a group but the group had already stopped meetings. But finally instead of visiting a self help group for parents I had a totally new experience — 2 hours' meeting with people from "Anonymous Alcoholics and Drug Users" Club.

I found an active self help group thanks to the Administration of one of the City Districts. But there are not many parents who are ready to come all this way.

### **How do self help groups work in Russia?**

1. Who sets the groups up? The setting up and developing of the groups was different. Some groups came into existence with opening support groups for parents, others – developed from parental NGO's. In any case, women were initiators of such organizations and groups.
2. Who visits self help groups for parents of drug users? First of all, mothers of drug users. There are some difficulties with visits by fathers women try to involve fathers, but their categoricalness of opinion or detachment from problems through immersion into work, abuse of drugs or run away from home leads to situations when their participation in meetings ends after one or two times.
3. How does the group work? The group meets 1 or 2 times a week for 1,5 or 2 hours. The backbone is 5-8 people. Self help groups often work on a "12-step" basis (the focus is made on spirituality), because this programmer gained wide spread in Russia. Most of the time is spent on discussion of feelings, problems and experience of living through them. Parents very often read parables and then answer questions. Here is an example of one of the parables:  
*"A monkey had two babies. She liked one and disliked the other. Once people tried to catch monkey. She took her loved child and ran away with him and left the unloved one behind. The unloved child went into the thick of the forest and people did not notice him. The monkey jumped on a tree and killed her loved baby by smashing his*

*head against a branch in a hurry. When people went away the monkey went back to look for her unloved child but could not find him and she was alone."*

There are 1 or 2 persons who are facilitators of the group but there are difficulties because of it. During last years many self help groups stopped work because the same people xavor, facilitators for 8-10 years. But on the other hand, there is a positive tendency: participation in seminars in Yekaterinburg, Kurgan, Chelyabinsk proved that there are enough people among parents from self help groups who are ready to set up new groups and be facilitators there.

4. Who supports such groups? First of all, Administrations of City Districts. They give their support by providing with a venue for meetings or inviting specific specialists: drug and alcohol abuse doctors, psychologists, social workers and psychotherapeutics. The negative side is the absence of specific specialists who can provide constant support for facilitators of such groups. Religious associations and organizations support such groups but these groups have a religious focus. The major effect from work of such groups is possible only when some social structure or NGO supports it.

### **What situation is there in Russia at the moment?**

1. There is access to information related to the activities of self help groups but there are some difficulties. There are various approaches to work with parents but there is no clear definition of concepts, for example, confusion between self help groups and support groups. What is also difficult is the confusion in terminology: Russian specialists use the term "groups of mutual self help" instead of "self help groups" associating the word "self" with being selfish.
2. There are also various self help group models. The question is what is right and what is not? For example, many self help groups in Russia are religion-based but this fact repels many parents from visiting such groups.
3. Specialists also speak about access to international programs but not all these ideas can be implemented in Russian situation and society.
4. There is also lack of adequate number of experts on setting up and developing work of self help groups for parents. Specialists and facilitators who work in self help groups need specific training. If there are professionals and experts on self help groups, this will help to more effectively develop work between official institutions and parents of drug users.
5. Of course, there are excellent professionals in; Moscow, St. Petersburg and other cities in Russia but poor cooperation in these questions between specialists from cities and specialists from rural and remote areas.

In spite of various difficulties there are a number of factors that contribute to further development of self help groups for parents of drug users:

- It is the huge potential of parents from former and existing groups and their wish to create new self help groups. Despite the disintegration of many groups the parents recognize the significance of such form of help.
- People are ready to adequately accept problems of parents of drug users. At a t, it was condemnation of parents of drug users but at present — it has become a wish to support them.
- There is an interest of official institutions to develop self help groups and a possibility to include them into municipal and state programs.
- And one of the most important factors is setting up support networks for parents of drug users. The "Drug Prevention Support Network for Parents and Specialists" is an initiative implemented in Russia by the Pompidou Group of the Council of Europe. This program has 3 pilot projects; one of them involves setting up and developing self help groups. Firstly, in framework of this program specialists of various institutions and NGO's from two Russian cities had received training both in Russia and Norway to work with parents and self help groups. I want to thank my Norwegian colleagues — Mr Arne Andresen and Mrs Carol Cortese — for organizing these trainings with the involvement of the best Norwegian experts. Secondly, after attending these trainings the group of specialists became trainers for other specialists and parents in other

Russian cities — Kurgan, Chelyabinsk and Yekaterinburg. Thirdly, Norwegian experts have developed a handbook "Planning and initiating mutual self help groups in the field of drug demand reduction" which at this moment is being adapted by Russian experts and will be soon available for Russian specialists and parents.

The "Drug Prevention Support Network for Parents and Specialists" does help Russian specialists to get access to information, make possible training and exchange of experience between different self help groups for parents.

The mentioned factors indeed contribute to development of self help groups for parents of drug users in Russia, but there is necessity of application of other ways for improvement of such system both in Russian and international levels, for example:

- These are training for Russian professionals by foreign experts under Russian conditions and appeal of attention not only to capitals and big towns but to small ones, remote regions and rural areas in Russia.
- It is also crucial to involve Russian experts working with self help groups to participate in international self help networks. This should also include the participation in training activities as well as the development of new on-line and Internet recourses.

Perspective of such form of work is obviously and very significant at this moment for Russia and Russian specialists are ready, for changing's and perception of foreign experience.

## **Work shop I - group sessions**

### **Are there Fundamental Values for Self- Help Groups?**

*Introduction Sociologist Anne Diemer, Denmark*

*Starting self help work, is about making a product.*

#### **The values of self help work**

- Which are they?
- How do we practice in our everyday-life?
- What are our guiding stars?
- Is it something right or wrong?

#### **Is this the main values?**

- Voluntary work (frivillighet)
- Equality (likeverd)
- Engagement (engasjement)
- Mutuality
- Loyalties – taushet

#### **Task for the group session**

Introduce your self – select a secretary (not a leader).

Make a brainstorming – not a discussion – write everything down.

Each member of the group selects five words.

Use these five words and give examples from your daily life.

The group should agree on five words that describes the values in the self help work.

- Values in self help groups
- Values in supporting self help groups

#### **Group presentations:**

##### **Group 1**

- Diversity
- Equality - is it a universal value?
- Mutuality
- Self responsibility and mutual responsibility
- Participation, commitment, engagement
- Personal and social change (rights, political activism)

##### **Group 2**

- Shared responsibility
- Common concern
- Empathy
- Mutual respect
- Acceptance (of the feelings of the other...)

##### **Group 3**

- Mutuality - sharing mutuality
- Independence. The participants must have the ability to find and develop their own strategy when working within a group. Nobody has the right to tell others what is right or wrong.

- Participation
- Voluntary – personal benefit of the participation
- Respect

#### **Group 4**

- Learning capacity. A profound belief in everybody's possibility to learn.
- Confidentiality – I own my own problems.
- Empowerment
- Change of attitudes
- New perspectives on your own problem
- Self-belief/ hope/behavior
- Equality (responsibility)

Belgium

## **How do we Communicate Self Help in Belgium?**

Mr Peter Gielen

One of the remarks from the previous expert meeting in Zurich that I still remember very well, is Elzbieta Bobiatynska's expression 'self help is not sexy'. That is why for Poland Elzbieta rather prefers the designation non-governmental organization over the shadowy perhaps corny word self help group or self help organization. This remark is the immediate starting point of my short introduction on how we communicate self help in Belgium.

But first I would like to restrict or refine the title of my introduction into "how do we communicate self help groups in Flanders". Not Belgium but Flanders, the Dutch speaking part of Belgium. Not 'self help' but 'self help groups' since self help is a very broad term that in our society is all too often confused with self-care. Communicating self-care in Flanders would quickly lead to promoting self-medication, self-diagnosis or recommending self help books such as "The feeling good handbook" or the still to be published book on 'how to quit smoking in fifteen days using Norwegian herbs and Tibetan elevation techniques'.

In other words, our field of activity is not self help or self-care - the differentiation between these two words in Dutch is vague and difficult to interpret. Our working area is self help groups. And even so, many associations that we, professional self help supporters, call self help groups are not pleased with this designation. They rather call themselves patient association, league, working group or for convenience sake, simply "association for ...". They too dislike the double connotation that also the word self help group contains. On the one hand the connotation of self help as self-care, some form of amateur health care or therapy. On the other hand they dislike the popular connotation of self help group as just a small number of people around a table with coffee and Kleenex who do nothing more than complain to each other about their health or another problem.

In other words, most Flemish self help groups don't like the fact that their work is often reduced to 'just talking' since they are doing so much more: informing people, offering individual support and services, defending interests, and so on.

So, returning to the adjusted title of this introduction, just a short sketch of how it was 'in the beginning'. Twenty, twenty five years ago, during the boom self help groups in Flanders, it wasn't really difficult to attract media attention for some new self help initiative. In those days, the foundation of such a group or the appeal of a few people to together start such an initiative was still interesting for the Flemish newspapers, magazines, radio or television. Such a start and foundation answered to the principles of newsworthiness. The start of self help groups at that time was something that deviated from what was normal: ordinary citizens setting up care and assistance besides the well developed professional circuit. At the same time, these events touched a large number of people since the first self help groups were associations around common diseases and circumstances: diabetes, rheumatism, heart diseases, or Crohn's disease. In addition, the story could perfectly be linked to the personal life of the initiator, often someone with a harrowing life's story full of sorrow and incomprehension.

Furthermore and adding to the newsworthiness, the start and foundation of self help groups fitted in with the awakening criticism towards professional service delivery (impersonal, suppressing, bureaucratic, paternalistic, preserving the established order, ...).

So, twenty, twenty five years ago, the start of self help groups still had news value and the fact that self help groups that were being initiated were given media attention stimulated and confirmed other people to also start an association around their problem. So the start of some groups triggered the initiation of many more; a kind of snowballing effect. The fast development of self help groups of all kinds also produced some attention from the general media for self help support.

On the other hand, self help groups as a concept didn't have much news value for the general media in Flanders twenty years ago. It still hasn't. For that, the concept isn't straightforward enough, its effect on the average population is hard to assess, and it is much more a development than a (sudden) incident. All in all, self help groups as a concept is to

abstract to be a news item. For the same reasons, the work of self-help clearinghouses, facilitating and supporting self help groups, is irrelevant for the general press; it is also "not sexy".

For the rest of this introduction, I would like to distinguish "communicating self help groups" and "communicating self help groups as a concept, a method, and an idea".

### Communicating self help groups

The start of once again a "new" self help group around such and such health or welfare problem is not keeping the Flemish media awake these days. There's only interest when the theme the group is focusing on is so unexpected or different, that this in fact constitutes the news value. Not so long ago there was a lot of media attention for a starting group on asexuality. Not the start of the group was interesting, newsworthy, but the fact that there are people who are really not interested in sex and find sex so disturbing that they would like to do something about it. This is so far off the "norm" that it becomes interesting, that is had news value. A bit longer ago, there was a real media hype for a self help group for workaholics that started and also the activities or developments that the self help group on sexual compulsiveness wishes to announce through the general press can regularly count on media coverage.

The start of once again a self help group around abuse or yet another physical or social problem only sporadically gets a turn in the general media and only if a distressing story can be brought.

Advertising the start of new self help groups doesn't become any easier. Twenty years ago, a good press release was almost sufficient to attain general media coverage and take a flying start with at once a large number of members. Today this is very difficult for new self help groups. But also the existing self help groups and organizations find it very hard to attract attention from the general Flemish media. This means that both new and existing associations have to spend much more effort and creativeness to get their message, activities and undertakings across. In stead of a general promotional policy using the popular media (which means that others, journalists do most of the work for you), new and already existing groups need to conduct a much more precise and labour intensive communication policy than before.

For local or regional initiatives this still is manageable: they can work with the local or regional media (the fact that an initiative is local or regional for these media is already newsworthy), they can collaborate with local and therefore familiar and easier accessible hospitals or health service agencies to distribute their folders or posters, to reach potential members or participants through local or regional go betweens or referrers, to put their promotional materials in public places such as libraries, sick funds, and so on. So at the local or regional level it still is possible to design a feasible promotion campaign. Whether it can be implemented depends on the means and volunteers available.

Self help groups that are starting and also existing groups who target the whole of Flanders, for instance to attract members, to announce their activities, have it much more difficult than twenty years ago. The general, popular media are not interested anymore, large scale promotion aimed at the general public costs the earth and is very labour intensive. The concern of these self help groups is to reach their potential members at those places where they probably can be found. New groups in Flanders nowadays are often about rare diseases. For these diseases there are only a few treatment centres where most of the potential members are likely to pass one day (a centre for hereditary diseases for instance). Or perhaps there is only a small group of specialists working on a particular disease in Flanders (for instance for hemachromatosis there are only a handful of experts). In still other cases it is easy to identify the medical specialist whose at the centre of diagnosis and treatment (the neurologist with Guillain Barre's syndrome for instance)

The most appropriate way to announce these initiatives or spread their activities is probably to collaborate with these meaningful persons and institutions.

We find that for self help groups for which participants are not so easy to find around or to locate, the growth and development goes much slower than before. This is on the one hand caused by the fact that groups for common problems already exist and a big surge in membership is therefore unlikely. On the other hand this is also caused by the lack of news value of yet another start of a particular self help group. Thanks to good relationships with the press and our credibility, we nevertheless still manage to regularly attain media coverage. Still, the start of new self help groups develops much more gradually than twenty years ago and as a support centre, we try to prepare the initiators for that. Rather than emphasizing once-only promotional campaigns, we now opt for a sound public relations policy that aims at the same effects but on the longer term. I'll come back to this later.

To conclude this chapter, quickly some words about how existing self help groups despite their lack of sex appeal are still trying to get the media. They try to create news value by for instance involving famous people from the worlds of show business or sports as patrons of their association. Their presence or attendance at certain meetings or activities of the group is expected to generate media coverage. Or they try to link their points of view or demands to current political measures or recent events (savings in the health care budget for instance or a large gas explosion which put the organisation for burn victims in the spotlights). They try to organize mediagenic activities (climbing the Kilimandjaro by liver patients who had a transplant or the sale of celebrity stuff) or they claim media attention by formulating a complaint that is then debated in a popular TV-show. In short, by all kinds of creative means groups are trying to manufacture news value and through that attract media attention.

#### Communicating the 'self help group concept'

I already told you that self help groups as a concept, as a method perhaps even as a technique has no news value for the popular media in Flanders. That was the same twenty years ago. The general population didn't want anything to do with a conceptual description or a detailed explanation of how and why self help groups work. The fact that groups were initiated, the fact that they are still active and the fact that more than 250 000 people participate, speaks for itself. Communicating the self help concept to the general public is therefore not really an assignment for our support centre. When the opportunity does occur it is mostly done by referring to examples of successes and activities of existing groups. That's much more appealing than some theoretical explanation.

Creating a self help favorable climate with the people or organisations that can make or break self help groups, is on the other hand indeed one of our principal tasks. In the light of what I told you earlier self help groups do need allies and assistance; people who can refer possible members, can contribute material or financial means, who are prepared to defend the concept or justify it, who can support the group in one way or another. Examples of such people or institutions are obvious, , doctors, paramedics, social workers, psychologists and their professional, scientific and educational organizations, hospitals, sick funds, public agencies, counseling centres and so on.

Surfing along on the wave of interest for self help groups twenty years ago and armed with sound scientific research on the nature, presence, effectiveness a.s.o. of self help groups, our support centre during its first years spent numerous hours promoting the self help group concept with the earlier mentioned allies or opponents. Lectures, talks, interviews and articles in specialized magazines and journals, self help happenings, symposia, detailed directories our own periodical, joint projects and so on are examples of the instruments that were used. The fact that the government financed and recognized our centre (which it still does) and the fact that we were embedded in the university of Leuven (which we also still are) raised our credibility as sales representative for the self help group concept and also opened professional doors.

Anyhow, with the years our sex appeal and also that of self help groups, has generally diminished. Self help groups are there, the concept is apparently known, it is even copied and incorporated. Promoting the self help group concept is therefore not our most time consuming activity anymore. Promoting existing self help groups is only indirectly one of our

tasks (we try to support groups to promote themselves as good as possible). What we do now in this field is rather to preserve the accomplishments of self help groups and maintain a self help group favorable climate.

This we do on the one hand by ensuring that the Flemish self help groups are "strong", that they do a good job and are prepared for the present-day challenges (through offering information, education, customer tailored advice and support a.s.o.)

On the other hand, we try to preserve the accomplishments thusfar and maintain a self help favorable climate by developing a sound public relations policy in stead of conducting promotional activities. I told you before that I would come back to public relations. What we at this moment are trying to give to groups and what we also try to put into practice ourselves is a systematic public relations policy that is aimed at stimulating mutual understanding between ourselves, the self help groups and the other target audiences. In other words we don't advertise self help groups or ourselves anymore. What we are trying is to create relationships based on trust using accurate and sound information based on honesty and knowledge with all the partners in the self help group arena. This relationship based on trust guarantees us that together with these partners we can realize our goals in the long run.

Essential in that public relations policy is that you have good pr-instruments, that you specifically bring into action for your different target groups. Knowledge about these target groups is also very important.

The instruments we currently used are among other things, a periodical, a website, a detailed directory of self help groups in Flanders, brochures, educational activities, personal contact, taking part in or organizing symposia, meetings, speeches, and so on.

The target groups are practically the same as the allies of self help groups I mentioned earlier completed with people or organizations that are important for the future of our centre too, ministries, public officials, the university world, and so on.

So we're not promoting self help groups and we don't advise self help groups to develop expensive one-only advertisement campaigns. We choose for the long run with public relations. Carefull planning, a realistic image, knowledge and attractive presentation are the key notions in this.

Summarized and returning to the starting point of this short introduction: we are not sexy anymore, but thanks to our gentle character, we're still a bit attractive.

Greece

## **How do we Communicate Self Help in Greece?**

*Psychologist/Co-coordinators of Self help Promoting Programme:  
Lainas Sotiris and Fragiadakis Kostas*

### **A. Brief Description — Theoretical Background**

Self Help Promoting Program is being implemented under the supervision of the Social and Clinical Psychology Section of the School of Psychology, Aristotle University of Thessalonica. In particular, Dr. Ph. Zafiridis, psychiatrist-Associate Professor of Clinical Psychology, is the scientific supervisor of the Program while Dr. K. Bairaktaris, psychologist-Associate Professor of Clinical Psychology, is the Scientific Supervisor of the psychosocial interventions which are being implemented.

The program is funded by the Greek Organization against Drugs (OKANA). The Program was initiated in February 2001 and is located in Thessalonica, the biggest city in Northern Greece with approx. 1 million inhabitants. Its basic aims are:

- Promotion of Self Help approach with regard to substance abuse and other psychosocial problems,
- Sensitization and training of health professionals regarding Self Help and its applications,
- Research into the applications of Self Help in confronting psychosocial problems.

Self Help Promoting Program is grounded on the gained experience and theoretical underpinnings defended by members of the Social and Clinical Psychology Section of the School of Psychology, regarding the confrontation of contemporary psychosocial problems (Dikaiou M., Zafiridis, Ph., Kordoutis, P., Bairaktaris, K., Boni, E. & Papadopoulou, D., 1999). Indicatively, both Scientific Supervisors of the Program are pioneers in their relevant fields of expertise; Dr. Zafiridis was the founder of Therapeutic Communities for substance abusers in Greece while Dr.

Bairaktaris was the person behind the de-institutionalization movement for psychiatric patients in Greece. Their work has been considered both pioneering and fundamental and follows the same philosophy which underlies the Self Help Promoting Program.

This philosophy, resting on the axes of Critical Psychology and other critical movements and efforts (Scheper-Hughes, & Lovell, 1987, Fromm, 1956, Yablonsky, 1967, Albee, 1998, Sarason, 1981, Fox, 1991, Prilleltensky & Nelson, 1997), states that the dramatic increase of psychological and psychosocial problems (W.H.O., 2001) together with the observed inadequacy in the professional models developed for their confrontation, is associated with structural aspects of our economic / political system, with its internal contradictions, ideological trends and persistent choices. Problems such as drug and alcohol abuse, the increase of serious forms of mental illness, adolescent transgression and suicidal tendency, juvenile delinquency, alienation, violence, old age alcoholism and so on, nowadays evident at unprecedented levels, are only but the symptoms of a system in crisis (Prilleltensky, 1989, Zafiridis, 2000). The prevalent developmental model is based on and further promotes a series of attitudes / notions, ranging from competition by all means, the centrality of wealth as the core societal value, to high work and living intensity in general. As a result, this *modus vivendi* brings about passiveness, loneliness, and depersonalization while excluding those who cannot cope with these inhuman demands (Bairaktaris, 2004). This model also constitutes a breach in basic human needs fulfillment such as the need for companionship, solidarity, honest and sincere relationships, and collectivity. The steep increase of individual psychopathology and by extension of psychosocial problems is mainly attributed to the failure to cover such needs (Zafiridis, 1987, 1988).

Self Help proves to be a reliable alternative solution, since its basic building block is the activation of citizens in coping with their problems within a framework of collectivity and solidarity (Katz, 1981, Riessman, 1997, Matzat, 2001-2). Focusing on the centrality of self-activation and the assumption of personal responsibility, Self Help dissipates the currently observed passiveness when dealing with health matters. Apart from the above-mentioned contribution, the effectiveness of Self Help groups is also determined by the significance of

people "meeting" each other and forming communities of persons as opposed to impersonal "cases" which simply fit inflexible diagnostic categories. All these factors favour the growth of humanistic values and promote the fulfillment of basic needs which are prerequisites for mental and physical health maintenance and self-actualization.

This new approach, by placing the directly involved persons in the centre of action, redefines entirely the role of the health professional. Within this framework, health professionals are to reconsider traditional models of prevention, therapy and rehabilitation, which keep patients passive and, in reality, perpetuate the vicious circle of health problems themselves. By intentionally interlinking health care and social growth, professionals' new role is delimited to the encouragement and facilitation of activated citizens based on the agreement that only through the active and responsible involvement of those concerned, may health problems be confronted. The discharge and subsequent liberation of health professionals entail the acceptance of a new model of coping with health problems. This model overcomes the existing impasse, by placing citizens and local communities in the core of action, and health specialists in the periphery. The specialists are entrusted with the role of embracing the initiatives of citizens and local communities by providing know-how (Zafiridis, 2000).

### **B. Current status of Self-Help in Greece**

Self Help in Greece is not particularly widespread and it definitely does not possess the expanded form of a movement. The whole debate is still at an initial stage. In contrast with other countries, no national policy and planning exists for the development of Self Help groups. With no intention to sound arrogant, the issue of Self Help was first raised by the Self Help

Promoting Program in 2001 when the first efforts to offer a support framework to such initiatives have been launched.

It is also important to note that there is not a consistent survey on existing Self Help groups in Greece. Only patchy information can be obtained from various sources which fail to reveal the whole picture mainly because Self Help groups are new in Greece and the definition and taxonomy of such groups is often confusing. When starting in 2001, we realized that this confusion is not attributed to conflicting views over specific aspects of the notion, but mostly to fundamental divergence from the substance and meaning of Self Help. One of the most persistent problems is the assignment of leading roles to experts while keeping the term "self help" at the forefront of such groups. At the beginning, our basic intention was to change this attitude through participation in conferences and seminars as well as through the training of the experts themselves.

The number of Self Help groups is not large, even though an increasing tendency is recently observed. Apart from clear Self Help groups, several other collective initiatives of self-organized citizens were formed regarding health issues. These initiatives mostly take the form of associations, unions and volunteer organizations. Some adopt Self Help and self-management practices in one or more of their axes of intervention. The exploration of and acquaintance with these groups is one of our activities as will be presented in the following. The above mentioned initiatives are extroverted efforts with special focus on the defense and assertion of rights.

In the following, we present the main types of Self Help groups:

- a. 12 step groups: These form the oldest and mostly widespread type. They date back to 1987. It is estimated that there are around 70 groups in the country which operate in 19 cities (Alcoholics Anonymous, Narcotics Anonymous, Families Anonymous, AI-Anon, Overeaters Anonymous, Adult Children of Alcoholics).

- b. Other Self Help groups: Self Help Group for Multiple Sclerosis, Self Help Group for Young Patients of Diabetes (under formation), Self Help Group of disabled persons called Disability Now, Parents' Association for Mental Health.
- c. Associations of People with Physical Illness or Disability and of their family members: These associations, in relation with the exact nature of the problem concerned, deal with the empowerment of their members, sharing of information on potential ways for the confrontation of the problem, education, general public sensitization, prejudice elimination, and the improvement of the quality of life.
- d. National Federations: These Federations promote issues of general concern and deal mainly with representation, advocacy, the defense of rights and the promotion of policies. One of the most active Federations is the National Federation of Disabled Persons, which was founded in 1989 and counts 39 member associations. Its administration is entrusted to disabled persons and to parents of disabled persons.
- e. Associations which are created around institutional bodies: These involve associations which function at the periphery of central structures or services and they essentially support their operation. Any change in the philosophy and operation of the central structures affects these peripheral associations. Examples are the "Family Associations of the Centre Therapy of Dependent Individuals", the "Parents of Addicted Persons participating in the Recovery Program of the Psychiatric Hospital in Attiki", and the "Friends Association of the Psychiatric Hospital of Thessalonica".

### **C. Presentation of Main Fields of Intervention**

#### **C.1 Open Program for the Psycho-social Support of Psycho-active Substance Users and Family Members of Users**

As already mentioned above, the Program's basic goal is the promotion of Self Help in the confrontation of drug and alcohol abuse. In this framework, we have developed the Open Program for the Psycho-social Support of Psycho-active Substance Users and Family Members of Users.

From our perspective, this open Program offers an interesting example of an innovative psycho-social intervention along the lines of Self Help philosophy and its applications. Its function is twofold; on one hand, participation in 12 steps Self Help groups and, on the other, simultaneous support towards people in fields which are not met within the framework of the groups. Program's activities are planned in a participatory mode by staff members and group participants with the intention to meet the needs of the latter. This participatory mode is based on the concept of co-formulation which is entirely consistent with most modern health policies (Bairaktaris, 1994). In particular, Program's actions are not applications of theoretical models and plans from the expert's side, but a product of constant interaction among involved and interested people at any given time.

#### **Below we present the main activities developed:**

- a. Sensitization on the notion of Self Help and its application in the problem of addiction. This activity is realized through the active interconnection among people which are not aware of the Self Help groups but keen to participate and people which are already participants in such groups and in need of further support frameworks. The term active interconnection refers not only to the provision of information on the time and place of Self Help groups meetings but also the linkage of newcomers with older members and the opportunity to meet with other persons participating in Project's activities. This active interconnection is also promoted through the participation in the other activities which are based on the principles of self-management and mutual aid.

- b. Creation of a safe and "clean" from substances meeting place. The focus is on developing communal values such as solidarity, honest human relations, sincerity, mutual aid; all values which promote personal development.
- c. Medical and legal support, educational and professional development advice.
- d. Organization of computer and foreign language learning seminar
- e. Awareness-raising on cultural, social and ecological issues.
- f. Facilitation of Self Help groups' function (this activity concerns not only Self Help groups dealing with addiction problems but also with other problems).

### **C.2 Provision of know how on the creation of Self Help initiatives**

With the fundamental intention to promote the notion and applications of Self Help in the confrontation of psycho-social problems, we have planned and implemented since February 2001 the provision of know how on the creation of Self Help groups. At a first level, this support is addressed to people which face health, mental or physical, problems. At a second level, we aim at the empowerment and training of newly-created group members in order to enable their future autonomous and independent function.

In this regard, the following actions have been implemented:

- a. Creation of a database with existing Self Help groups regarding various problems.
- b. Collection of bibliographical references concerning the creation of Self Help groups.
- c. Preparation of a manual on simple steps for the formation of Self Help groups which is distributed to interested persons. This manual forms the basis of any collaboration with interested persons.

### **C.3 Psycho-social Interventions based on self/mutual help principles. Community work and prevention.**

The development of interventions which address psychosocial problems at the community level is also significant. The basic idea is to involve all possible stakeholders in both phases of planning and implementation. In this regard, a series of pilot interventions have been implemented in various schools of the city. Our intention was to enable communities in addressing a series of problems, ranging from psychoactive substance's use and abuse and teenage violence to racism, xenophobia and problems related to the coexistence of native and foreign students. It is important to note that the whole intervention was based on the active participation of all staff members involved with the educational process.

### **C.4 Diffusion of Self Help notion to the general public**

The sensitization of the general public on the notion of Self Help is another main field of activity. As already mentioned, the notion of Self Help is not particularly widespread in Greece, which results in the existence of several difficulties in Self Help groups growth. Along these lines of thinking, a series of publicity actions have been developed which aim at the presentation of Self Help core values.

These involve:

- a. The operation of a Program web-site ([www.selfhelp.gr](http://www.selfhelp.gr)) where information on Self Help initiatives and relevant issues is provided.
- b. Regular interventions in the media regarding the Program's activities and the notion of Self Help in general (articles, interviews, etc.)
- c. Participation in local events and associational meetings where the public debate on such issues is fostered.

### **C.5 Community Networking**

This activity brings together people or groups of citizens/employees which adopt in practice the principles of self-management, self-organization, and active participation in social,

cultural and environmental issues. In order to ensure the diffusion of the Self Help notion, we first attempt to bring together people and groups which function along these lines. As demonstrated by the Program's experience, Community Networking contributes in a two-fold manner; by fostering the formation of Self Help groups and by facilitating the function of existing initiatives.

### **C.6 Networking with Self Help groups**

There is not an updated database of Self Help groups and initiatives based on the principles of self-management in Greece. An effort to address this lack of information has been undertaken by the Program with the intention to trace all relevant initiatives in Northern Greece. Tracing down these initiatives implies getting in contact and actually meeting each separate group with the intention to present their work along specific axes/criteria such as participation framework, funding status, institutional form.

### **C.7 Training of health professionals**

The basic intention is to train health professionals towards the adoption of new roles, namely the support of peripheral initiatives and the empowerment of citizens. The principles of Self Help are presented in the curriculum of training seminars, while staff members offer tutelage and share bibliographical references with health professionals which create self-managed groups within their working environment. Within this framework, formal educational modules for under- and post-graduate students of Psychology and for graduates of Social Sciences are offered at the University level. Another activity regarding the sensitization of health professionals is the effort to provide information of all health professionals working in hospitals, other health facilities, or privately about self help philosophy, its applications, self help groups that exist in Greece and about Self Help Promoting Program. Training and educational development is further enriched through the participation in conferences and seminars and through publication of articles in journals and newsletters

### **D. Current difficulties and future prospects**

Given that the diffusion of Self Help notion in Greece is a new effort with a short history of four and a half years in parallel with the initiation of the Self Help Promoting Program, a number of deficiencies and difficulties exist. The most significant are the following:

- The lack of any state policy regarding the development of Self Help groups.
- The lack of knowledge on behalf of health professionals regarding Self Help and its applications.
- The lack of complete database of existing initiatives.
- Inadequate networking among Self Help groups and initiatives which operate along the same lines.

Having said that, the future challenges are presented in accordance with the following axes:

- Diffusion to a greater extent of the philosophy and practices of Self Help among health professionals. In this framework, the Faculty of Psychology, after the approval of the Greek Ministry of Health and Social Solidarity, is going to implement in the following two years a Project for the vocational training of professionals which are located in various public services (health, welfare and employment promotion) in Northern Greece. Self Help and its practices are at the core of the vocational training curriculum.
- Tracing down of existing Self Help groups and similar initiatives in Greece and the promotion of their networking.
- The upgrade of the existing Self Help Promoting Program to a Self Help Clearing House, given that existing institutional funding addresses only addiction problems

whereas we simultaneously promote Self Help initiatives to a lesser extent in a variety of problems.

- Advocacy at the central level in order to include in the health policy agenda the issue of Self Help. Having said that, there are concerns in our Self Help Promoting Program regarding the potential danger of having Self Help incorporated by the dominant welfare model. From our perspective, such an evolution invalidates Self Help as a movement of concerned and activated citizens.
- The utilization of the gained international experience. Given the brief history of Self Help in Greece, efforts for the promotion of Self Help can substantially benefit from the exchange and utilization of international experience through networking with similar initiatives abroad.

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Sweden

## **Communicating Self Help in Western Sweden**

*Bjarne Rehnberg – Frivilligsamordnare, Primärvården*

My name is Bjarne Rehnberg and i am a coordinator of selfhelpgruops and of other forms of voluntary social work in a specific part of Sweden.

First, I think it is essetial that I define what I mean with the terms selfhelp and selfhelpgruops, because I have learned that we mean differnt things with these words in differnt parts of the world.

So, - when I talk of selfhelp groups, I talk about discussion groups.

I mean groups that normaly sits round a table and discuss a problem that the groupmembers all share. In Sweden we followed our danish frends in their method, as we learned it 10 to 15 years ago. Our groups are rather independent, they have any leader and they dont belong to any church, party or organisation, Our selfhelp groups are trying to use much of the same method as Alcoholic Anonymous AA.

Sweden was one of the last countries in the western world to embrace the self help concept. There are of course a lot of reasons for this and for the difficulties we have had to get it working. I can mention some of them, which I think is the reason for this late awakening.

First.

One is the fact that we have a very good publicly financed social service to the Swedish people, which means that the Swedish people is used to find a publicly paid helper somewhere in the system and we are therefore not used to have to do too much ourselves. And to find someone outside the systems to talk to is something that is very unfamiliar to the Swedish people. We are simply not used to talk to other people about our problems. We don't have the same tradition as maybe you can find in other countries.

Second.

Another reason is that we have an enormous respect for the educated. Which in this case means that if you, as a helper, should be considered able to handle someone's confidence and inner thoughts; you must at least be a fully educated psychologist with an acceptable number year in practice.

Third reason.

From the experiance I have with selfhelp groups in "my" area, and I will soon explain witch this area is, I also find that it is much easier to start a selfhelp group in a city than in a rural area.

And we don't have that many people per square mile in Sweden as you have in Germany, Britain or Holland. So with a few exceptions the greater part of Sweden is to be considered as a rural area.

And finally.

**If** there is something that you can call a national character, with which you mean that this is the way that most Swedes or most Italian or most Polish people are, -- and I am aware of the fact that new research says that it is doubtful, but still, **IF**, these national character exist, than we must confess that the Swedish people are the quite type. I think that we often are considered to be quite, reserved and withdrawn and none of that is of course beneficial for starting self help groups.

"My" area is the northern part of the west coast of Sweden. It consists of 15 communities or districts all with a relative high degree of self-government. Two of these communities are towns with a population of over 50.000 people but the rest are small, with a population ranging from 10.000 people to 30.000. This area measures about 130 km from north to south and 100 km from west to east and in it lives about 270 thousand people, which aren't much, it is only the size of a normal European city.

"My" area is what you are passing through if you are leaving Oslo, going south. It starts when you pass the Swedish border and it ends some 50 kilometres before you reach Gothenburg.

But of course, this is a large area, geographically, and it is impossible to be in all 15 places at the same time and I therefore work together with different networks in these communities. These networks consist of different people and they differ from one place to another. Mostly in it, you find the district health coordinator; you can find an adult education company, maybe someone from the church, a volunteer and so on. These networks are the ones that *actually* start the self help groups and my job is to keep them motivated, give them advertising material, educate them and organize cooperation between these networks. I have found that the role I have, as facilitator and helper, is a very important role, to keep this work going. Without it there is an obvious risk that the self help work will die from suffocation in these small communities?

The work with self help groups is growing in Sweden. It is not growing fast, but it is growing and we must remember that the self help concept still is young and fragile in our country.

Because the self help concept still isn't something that is obvious and natural for the Swedish people, our first and biggest problem is the marketing of the concept. We cannot advertise for a specific group, without first having explained what a self help group is. And this makes it expensive and it makes it hard for us to come in touch with our customers, specially in the very noisy media sound we have today. We simply have neither the money nor the knowledge to compete with the enormous advertising companies.

Again I will stress that this job is done by a local volunteer in a small community with a population of say 15.000 people.

Of course our marketing efforts would have been much simpler if we had felt the support and help from the official Sweden, the - government and their administrations.

But this is not the case in Sweden. I cannot see that we have this support today, neither with financial help, nor with practical help or with moral support for that matter. As a small local organisation you are very much "on your own" in Sweden, with the people and with the money you have managed to find locally.

As an example I can say that my job is the very rare exception in Sweden. There are not many of us around, of publicly paid facilitator for this kind of job.

Another result of this lack of national support is that the self help concept is growing only locally. There must be a volunteer or a voluntary organisation that starts in his or her town and we are all dependent of a local financial support.

This is also the reason why I stand here before you today and only talk about "my" area. I am not talking about what happens in all of Sweden, simply because I don't know. And there is unfortunately no one else who knows either. There is some research going on, on university level, where they are trying to calculate the number of self help groups started in Sweden. But today no one can say how many they are and how they work.

My way of communicating self help in western Sweden is therefore mainly through these networks. But of course we also have an internet sight and a newspaper.

As said before self help is growing in Sweden. Every time I look on the internet I find new sights, and I also hear different reports from "new" towns, where they start self help groups. So it is growing.

And still, it is of course frustrating to see that a brilliant idea, as the self help groups are, is not given the opportunity and the chances that I think they deserve, but maybe there is something good in it.

The self help groups in Sweden can grow from zero and in its own speed and develop so that it fits the Swedish way of life, and maybe the self help group in Sweden therefore have a better chance of survival.

Thank you.

Denmark

### **Self Help Groups Interplaying with the Surrounding Society**

Sociologist Anne Diemer - Manager of Volunteer Centre/Self help project.

In Denmark we have experienced that a synergy effect may arise between self help work and the surrounding society.

We have seen that bridgebuilding from shgr to other parts of the volunteer world, to the professional therapeutic world, and to the public, municipal and state institutions gives all participants in the cooperation development in quality, creates new knowledge and more networks among people..

A conscious wish to cooperate with other associations and systems must be balanced by a realistic knowledge of who we in the world, what we want to develop/attain, and therefore what we want to cooperate about.

I will deal with:

1. From shgr to society
2. From society into the group
3. Joint efforts: shgr and volunteer centres together
4. Cooperation, locally and nationwide, Frise
5. Concluding remarks.

Some of the magic in shpgroups is, that participants experience, that out of sadness, sorrow, pain and loneliness grows hope and new life.

Out of chaos and tiredness grows (relative) order and ability to act. Out of despair and loneliness grows kind companionship, sometimes friendship.

The local society gets more active citizens, pt's associations get more members, the local society gets more volunteers.

We have experienced that careful and conscientious cooperation with other parts of the volunteer world, and the professional world, results in more shgroups, new items for groups; and again, that shgr feed more volunteers to the surrounding volunteer world and create new methods in the professional therapeutic world.

The mutual inspiration develops a lift in quality in both end of the cooperation- bridge.

1. From group to society: Participation in a shgr may give participants the courage
  - to become volunteers: Second Hand shops, social cafés, visiting friends etc.
  - to participate as a group or individually in cultural activities, sports, outings
  - to start an education
  - to become creators of art
  - to get a job
  - To change home: move, also into a collective

2. From society into the groups:

Shgr are about feelings, we all know that! But they also are a perfect setting for getting relevant knowledge about one's situation: a group may need a professional teacher/informer to get relevant knowledge. Instead we offer the groups a visit from a professional specialist, who can inform them about precisely their questions: The overweight group has a visit from a dietist, the group of divorced women (who initiated the divorce) are seen by a psychologist to guide them on the question of guilt. The walking group (eleven years practice every other Sunday!) was "exercised" for a couple of months by a physiotherapist.

These professionals sometimes want a salary, but often they will come for free, because they know that group learning pays in other respects! Ask them!

Let us not forget to give the groups "good ideas" via the group starter, or the sh centre: as always in our work, we should not give advice until it is asked for!

Suggestions: Become a volunteer (Have brochures ready). Go for a walk together. Join in cultural activities; cook and eat a meal together, and so on.... all according to the participants' taste

The thing is to support the group, if they ask for inspiration, in daring to leave the sacred group-talk and venture into the surrounding society. The groups get new inspiration; they see new aspects of themselves and of their community.

They help themselves and each other by having good experiences together as a supplement to the group talk.

### 3. Joint efforts: Sh and volunteer centre together

One way to build a bridge between the groups and the larger volunteer world as such is to have shgr and volunteer centre under the same roof; this makes access to both offers easy, and a lot of relevant information can be given when the need arises.

In DK we now have 25 joint sh/volunteer centres, and the government has this year and for the next two years reserved 49 mill. kroner to support the establishment of new volunteer centres, and they specifically encourage that the volunteer centre has a build-in shgr project.

One of our ways (Ålborg, Thisted a.o) to support and encourage cooperation in the volunteer world is to offer a joint introductory course to the public: Do you want to become a volunteer in shgr or other kinds of social volunteering? The result are very promising: most of the participants in the courses (two pr year for four years) become volunteers, some connected to shgr, others become volunteers in social cafés, visiting friends etc..

The course consists of 6 meetings, 3 deals with shgr, 3 are study visits to volunteer places: social cafés, a street kitchen for addicts etc.

If anybody should want to get a model for this course, let's talk afterwards.

#### Joint Introductory Course:

Everybody interested in becoming a sh group starter or another kind of volunteer, is welcomed in the course. The course is led /taught by employees and volunteers We meet six times. Three lessons deals with "how to start a shgr"; three lessons are visits to three different volunteer" places" in our city, chosen by the participants in the course: Social Café, crisis-centre for women, a "street-kitchen" for addicts etc. The visits are pre-arranged, so we are sure not to disturb and that we are welcome!

The participants in the course are naturally free to choose a job, or to decide that they are not interested in volunteering. Maybe they want to join a shgr as a member?

The results are very good: The volunteer-organisations get more volunteers. The shgr get more participants. More citizens get to know about the volunteer world.

#### Project Another Life.

A quite new example of cooperation between sh principles and the surrounding society are: Project Another Life:

Anni: Doctors and/or social workers inform patients suffering from cancer/serious heart decease on leaving the hospital, that they are welcome to join a study group There will be around ten participants in the group and as many relatives in a parallel group.

Both groups will (together or separately, as they decide) receive knowledge by doctors, dietists, therapists etc

They will form their own shjgr to share experiences and thoughts. They will be introduced to the volunteer world (pts' associations, local as well as nationwide) They will start their own activities: exercise, cooking and eating meals together-

The principle is that of a shgr: The members own the group, and they decide how to use it. In this first pilot project there will be a project coordinator, Anni Pedersen, who has a short description of the project, you are welcome to take one! The idea was conceived by Sussi Maach, whom some of you met last time in Zürich, consultant for Frise, and she sends her love, our nationwide joint association for shgr and volunteer centres

### 4. Promoting cooperation nationwide: Frise

In order to get good results we need to be very good at working together. To

cooperate with other associations and the public system we need to be very aware of who we, the self-helpers, are, what we want and what we don't want! We have to be conscious about our values, our ethics, and we have to be realistic: We are a small part of the social landscape. We have much less power than the communal, municipal and state systems. We need financial support from "them".

The professional world has their ethics, rules, laws, budgets and knowledge based in theory. We have our ethics, hands and hearts, and knowledge based on experience.

Both parties have to stay in their own ground if we are to play well together.

This takes time, but it is worth while to deal with questions like:

What is our vision? What are our values? What do we want to cooperate about? And why?

An example: Groups for kids whose parents are divorced.

We have of late cooperated with some school teachers and parents in order to establish groups (not self help, these are kids of 8 – 11 years) for children whose parents are divorced. It is an example of the necessary "bridgebuilding".

The Vol.House had tried several times to start this kind of group, without success.

Now the initiative came from a schoolteacher: she saw how the kids suffered during "their" divorce, the parents were so occupied with their problems, and the kids so loyal to both parents, that there was no room for the children to express what it was like to be in their shoes. The teacher in question had herself been in a shgr.

We met and talked. The parents and kids were informed, those interested came to a talk, and the kids were asked if they would give it a try. So far two groups have been carried through. The same two group leaders meet the group of kids; the parents are invited to join in the first and last meeting.

Now more teachers are aware of the possibility, and our volunteers get valuable knowledge.

Cooperation with patients associations:

We have a lot of joint shgroups, established in informal cooperation with pts' associations like the Cancer Society, Association for young pensioners etc. They see the need for a special group and the sh centre does the necessary work.

Whenever the sh centre has visitors who suffer from a disease /handicap, or have been met by social changes like having adopted a child, we find out if there exists an association with this item/ sickness. You would be surprised at how often there is one or more! We inform the citizen about the association in question, and very often they here get just the network/support/information they need. And the sh centre gets a valuable contact/ cooperation partner. Another thing is that there exists a lot of sh-based groups, in patients associations and in other settings, that offer shgr, but "sailing under other flags", that is with other names. Diabetes groups are called "motivationgroups", Osteoporosisgroups are shgr for people suffering from osteoporosis, and so on. Nobody owns shgr! We should not compete but cooperate.

Example of local PR cooperation: the Volunteer Market.

Once a year all the volunteer associations (well, around 25 of them) in our rural part of Denmark arrange a Volunteer Market. On a sunny (always) Saturday on the main towns main square. We share the room, but every association makes their own stand. A committee has seen to the framework: Money (not much), PR, the Mayor to open the Market, bands to play (brass is best in open air) and a fashion show naturally performed by volunteers from the second hand shops in town.

Our nationwide association for shgr and volunteer centres, Frise, has the last year, via Sussi Maach worked on and actually built very good new bridges for cooperation across borders:

Best Praxis

Frise has set the members ( 47 sh/volunteer centres) working on developing mutual advice for "best practice" on coordination of shgr, on daily work in a volunteer center, on leadership in sh and volunteer centres.

Inspired by our hosts, especially Solbjörg, Frise has applied to our Social Department for 2, 9 mio kroner to build bridges and develop sh:

- An Internet portal for all shgr in Denmark, from Frises members, pt's associations and other organisations. A complete list of existing shgr. A citizen wanting a shgr with a special topic will be able to find the nearest offer. She/he will also be able to write her/his own, not yet existing topic for a new group.
- To collect and spread out knowledge on sh. That means research, and hopefully the establishing of a sh. knowledge centre.
- To connect sh to the oncoming reform in preventive and health promoting developments in the coming new, bigger municipalities in Denmark (starting 2007) Here the aforementioned Project Another Life is very relevant!

#### 5. Concluding remarks:

We know that working with self help gives us power and courage to recognise what is inside of us.

By using energy to build bridges from the shgr to the surrounding society we become more aware of what is around us.

For a local community to have a sh/volunteer centre is a chance to develop new methods in social work, to reach further out among the citizens. The spreading of sh.methods-based as they are on commitment, voluntarily, equality and loyalty- is a promise of personal development for the professionals, a development of new networks among the citizens; and finally, more self confident and knowledgeable citizens is a strengthening of democracy.

## **Work shop II - group sessions**

How can an international self-help network be a driving force for the power of self-help in a health prevention perspective?

### **Group 1**

- Health promotion – what's that?
- International OPEN conference and more participants.
- European Expert Meeting - more knowledge transfer (e.g. internet)  
- also between the meetings
- Work with our own “underdog position”.
- Participate more in other networks e.g. Health Promoting Hospitals.
- Get the self-help topic on the agenda.
- Agenda for conferences: Do local and national level have different agendas?

### **Group 2**

- Promote programs to the European Commission to start self-help in new countries.
- International website
- E-mail network
- Translate accumulated and written material into English and make experiences accessible for everyone.

### **Group 3**

- Better support of local co-ordinators to prevent isolation
- More formal structures, regular and informal contact
- Share good practices across the borders
- Explore diversity: How to know more about how others work.
- If we are going to promote and arrange open conferences we must encourage diversity.

### **Group 4**

- Preventing health?
- What is self-help?
- Bottom up/gras root – or facilitated by professionals?

## **Future Perspectives on Self Help.**

United Kingdom

### **Participation in Cancer Self Help Groups amongst Black and Ethnic Communities**

*Mr Mark Avis and Seeta Patel, University of Nottingham*

#### **Rationale for Project**

- Lack of involvement of people from Black and Ethnic groups in self help
- Self Help Nottingham - required evidence for improving practice in supporting self help with Black and Ethnic groups

#### **Research Methods**

- Sixty-eight interviews with self help group members, self help group facilitators, health professionals and volunteers who work with self help groups
- Interviewed a range of people nationally from a variety of ethnic backgrounds

#### **Findings: 3 key elements of self help**

1. forming a sense of community with people in similar situation and overcoming isolation

*"...people have said we like coming because we feel we belong."*

*"It's about ...companionship on a difficult journey."*

2. learning about condition, making sense of experiences and finding ways to deal with issues

*"...I've got the collective of people I can identify with and they know what I'm talking about and giving me the strength to like work through certain problems and issues that are facing me and they're all in that self help group for certain one thing to help ourselves."*

3. Reciprocity: giving and sharing, finding shared experiences

*"...we both found that we wanted to now give something back and also something for ourselves and not just become an isolated cases but form something that we could help each other and the people there were going to come and meet us and talk about their experiences and not always sorrowful but also happy times."*

#### **Individuality of groups**

- various forms of self help
- range of different characters
- focus of change
- lifecycle

#### **Barriers to participation for Black and Ethnic groups**

- Perceptions of self help - does not fit with cultural beliefs
  - inward looking, selfish
  - 'eurocentric' - reflects white, European values and an individualistic view of life
  - different understandings and misunderstandings about illness
  - fears concerning confidentiality
  - disrespectful to family
- Access to self help group meetings
  - gender
  - generation

*“...the cultural differences between the how young people live in society oppose to the elderly in our society as opposed to the generation that are growing up and all of that (rubbish) unless they live in it I don't think they would understand it”*

- language
- venues and getting to meetings

- Not made to feel welcome in self help group

*“...the first time I walked in ...I just felt really like... an alien had walked into the room because they're sort of sat in little clumps and little tables and nobody got out of their chairs or moved and they just gossiped amongst themselves and I think I went and sat on a table on my own and it was almost like they thought what are you doing here”*

- Not being able to find shared experiences with group

*“So I guess sometimes a lot of .. some groups have preconceived ideas of how the journey's going to be. Your journey's different to my journey.”*

*“...when you lose your hair they offer you a wig ... they tried to give you a wig which is similar to your own hair, none of the wigs were similar to my own hair, you see all these services, they weren't catered towards Asians. ...when the hair started coming out that was the hardest fact to deal with especially Asian girls with their long hair and when it's all gone what do you do?”*

*“I was thinking they don't know how it is to confront racism. Very rarely that a white person would get racist remarks.”*

### **Making groups more accessible**

- neutral venue and location
- transport
- translators
- translated information

### **Good Practice: Creating a sense of togetherness**

- food
- helping people feel comfortable
  - arrangement of room
  - separate toilets
- buddying
- acknowledging and respecting differences
  - *“I was like I'm not in the right place, I shouldn't be here, she put her hand on my back she goes she's “really glad to see someone from your background at the meeting, I've never seen a Sikh at a meeting and it's really really good” and that really cheered me up really really, it made me feel welcome you know what I mean?”*

### **Good Practice: Learning from each other**

- listening skills
- confidentiality agreements
- looking for shared experiences
  - *“...to be very accepting of all the differences and the different attitudes and issues that come up, and not being dogmatic you know, saying there's only one way to do things, being a good listener; not always yakking off, but*

*actually listening, may be not saying very much, but saying something at the appropriate moment.”*

### **Diversity – enlarging options for people**

- difficulties of the term Black and Ethnic – masking and stereotyping
- meeting individual needs and finding common experiences
  - “I think in setting up a separate group you feel that closeness of your own people and we know what, you know what, you feel you don’t have to explain things further.”*
- supporting choice and a range of groups – reflect ranges of common experience
- diversity training – for groups and facilitators

### **Future**

- good practice guidelines
- seminars
- group visits
- conference attendance
- academic papers
- more research

## **Future Perspectives on Self-Help.**

Norway

### **A Course of Studies in Self-Help Ideology and Methods**

*Manager Jan Ole Bolsø, Centre for Patient Information and Education*

#### **Studies in self-help ideology and methods**

- the right approach to developing and promoting self help in Central Norway?

I am one more bureaucrat.

I am not an expert on self help.

My observation tower is the bureaucracy of the Central Norway Regional Health Authority, one of five regional health authorities in Norway.

I am in charge of the Center for Patient Information and Education, KPI.

We have three key fields of activity

1. to gather knowledge
2. to develop new knowledge
3. to spread knowledge

KPI sees self help valuable as an ideology and as a useful tool.

But we also see that we need education to help health professionals to understand and make use of the ideology and its methods.

I will in this talk attempt to explain why KPI wishes to take part actively in creating a study in self help ideology and methods, and why we wish to link self help to patient education. The study will – I hope – be put together by The Norwegian Self Help Forum and the university college of Volda.

#### **Patient education**

The health services affect health in two ways:  
directly through treatment and indirectly through education.

Treatment is to a large extent instrumental, but very often it is nevertheless dependent for its success on the patient and the actions of his or her family. This means that both the patient and the family need knowledge that can support the treatment.

There is also a need for patients and their families to be able to master all the situations in which treatment is not sufficient.

The health service therefore uses education to influence the patient's and the families' knowledge. If the education is successful, the patient and the family will improve their knowledge. This knowledge will ideally lead to changes in lifestyle that in turn will have a positive effect on their health. So is the theory.

The cognitive aspect is strong here.

In other words, the focus is on what kinds of information the group receives from health professionals, their peers and others and how this takes place.

#### **Self- help**

What then is my idea of self help?

One definition is as follows:

*“To enable oneself to make use of the natural resources that are to be found in every human being’s powers.”*

This supports my belief that self help focuses on the psychodynamic processes of each individual.

Here we are talking about processes that are based on emotions and feelings. That is, processes that are based on mental energy.

A common feature of self help work is both the belief and experience that has proved that everyone has *inborn resources that can be activated*.

In other words, feelings, attitudes and motivation are really vital elements in self help work.

The conclusion is that self help = progress and development.

We can say that self help is a process aimed at creating meaning.

### **The system vs the lifeworld**

The approach to and logic behind self help and patient education are different. This makes it crucial to bridge the gap between these two domains in one way or another – at least if they are to support each other.

The psychodynamic approach versus the cognitive approach is one way to look at the gap, but it does not help us when it comes to overcoming the distance between self help as a domain and the health service as a domain.

Another approach is to distinguish between the systematic and pragmatic rationale that underlie the health services on one side, and the meaning making and communicative rationale behind self help on the other side. As a framework to capture this difference, we can use Habermas’ terms: life world and system.

I belong to the system and there we are concerned with power, economy, rules etc.

We can offer and provide education, but we can’t make people learn.

Patient education is in other words a programme of action in the system.

In the life world it is communication and understanding that is the essential logic. As a mainly psychodynamic process, self help belongs to the life world.

In an educational context a person can – without breaking the rules – fail to participate actively in the learning process. He can be passive.

In a self help group that sort of attitude will not work, because the person in question is in opposition to the group’s fundament and it will most likely end either with him leaving the group or with the group breaking up.

We have a situation whereby even though the aims of both patient education and of self help to a large extent coincide, the approach is so different and the focus in the processes so divergent, that to begin with it is difficult to see how they can be linked.

To bridge this gap, we can return to Habermas and hence life-world and system. We are, at least when it comes to health, always living in both the system and the life-world.

Between these two “worlds” there must be communication, or in Habermas’ words: communicative action.

We are then in need of some kind of tool that can be mutual between these two logics.

At the moment, I believe that this mutual tool must be the concept of learning.

As a warning I will introduce another of Habermas’ terms: colonisation.

When the system tries to embrace the life-world, there is a pitfall

– the system can reframe the life-world according to its own logic, and at its worst remove the meaning – empty it. So when you dance with Thomas, Bjørg and me..... Know what you do.

### **Learning and Illeris**

Many people have tried to explain learning.

The explanations vary according to what is emphasised.

For us Illeris' model has helped to clarify the process and given us useful insights.

Illeris believes that learning, development, socialisation and qualification are identical and overlapping processes that will always be present in a learning process.

He means that you can put all theories about learning into this model.

So we have followed up by placing some key words from self help into the model.

**Awareness** is mostly a cognitive process

**Processing** is mostly a psychodynamic process

**Movement** is mostly a social process

Patient education focuses on offering fresh knowledge from outside (from a teacher).

In self help this same fresh knowledge comes from within.

In a self help context it is often said that the greatest resource is the patient's own pain and suffering. This reaches the other members of the group through it being told about, something which provides a basis for mutual reflection.

Self help belongs to the life world and is in the main a psychodynamic process.

Patient education is part of the system and is for the most part a cognitive process (perhaps because that is the easiest place to start in a system perspective?)

The interface between the life world and the system is therefore crucial – the communicative action.

The health services can contribute with the infrastructure to self help but for the system to take self help seriously it is necessary with a research-based understanding of what self help is.

This will not necessarily change self help as a phenomenon,

but it will in all probability change the way in which we describe self help.

This can be seen as an annexation of self help.

But it can also be seen as the development of self help as a method and an ideology.

### **Self help and the health institution**

If self help is to be accepted by the health service, the health service itself must see the value of it.

It can, for example, mean that the education of patients and their families must be strengthened. The consequence of that is that self help must be granted its organisational place in the health institution – in spite of the fact that a specialist health service cannot carry out self help in the true sense of the word.

Self help is something people do themselves and belongs to the life world.

I believe that the health services' role must be to function as a door-opener for patients and their families into the world of self help.

The health services must then find out what it means to be a door-opener and how to play that role.

As a door-opener you have to open up to the interface between the system and the life world.

I see at least two vital keys to achieve this goal.

**The first key is the role of the health professionals.**

How shall we as a regional health authority with a staff of over 20,000 professionals adopt this ideology and method?

If we are to make full use of self help as a method and an ideology, then we must:

- have staff who understand self help on self help's own terms, and who on this basis can start self help groups
- have even more staff who understand the ideology, so that patients and their families are pointed in the direction of self help
- have administrators who understand what the ideology involves and who provide the framework
- must co-operate with local authorities, user organisations, volunteer centres etc so that structures can be established and support offered at the grass-root level, where people live

### **The other key is a strategy for implementation.**

Here I find it necessary to link self help to a responsibility by law on which a lot of focus has already been placed.

The education of patients and their families is just such a task with an evolving infrastructure.

### **Self help education**

In the same way as the health services need to anchor their activities in research, so must studies in self help be based on research and research-based knowledge. Only in that way can it become a study at university college level.

This means among other things that learning theories must be given a prominent place.

As a counterbalance and expansion of the research-based knowledge, it is very important that the course builds upon experience-based knowledge.

A self help study must make use of existing know-how within both the voluntary and professional fields.

It will therefore be essential that such a study is based on the self help ideology and the tools that it has developed.

That is why such a study cannot be created without experience and theory meeting on an equal footing.

A really vital challenge for such study will be to build bridges over the gap in understanding that exists between the professional and the voluntary perspectives, in other words, between the system and the life world.

It takes me sometimes time to understand what Solbjørg means, but i\*m glad she is so stubborn.

### **Summary**

I believe that the advantages to be gained from making self help method and ideology available to health professionals are considerable.

The fact that health authorities and university colleges become involved will in my opinion not result in an instrumentalisation of self help.

It is my belief that the ideology is so solidly anchored in the life world that the system will not be able to annex the experience-based knowledge.

KPI welcomes such a study with open arms and will gladly play the role of both midwife and godfather. If the parents want me to.

And here there should have been of picture of Marlon Brando.....? Just as a warning....?????



## **Future Perspectives on Self-Help.**

Germany

### **Future Perspectives on Self-Help in Germany**

Psychologist Jürgen Matzat, University of Giessen

#### **SELF HELP IN GERMANY**

- approx. 80 million inhabitants
- approx. 100.000 local self help groups
- with 2 to 3 million members
- 75 % on health matters
- approx. 100 nation-wide self help organizations of handicapped and chronically ill people united in two umbrella organisations
- approx. 500 "green-addresses" of nation-wide self help related groupings
- approx. 300 self help centres / clearinghouses ("SELBSTHILFE-KONTAKTSTELLEN") in all major cities and districts
- "The fourth pillar of our health care system"

#### **Future perspectives for self help in Germany**

- more self help groups and self help organizations (plateau effect?)
- more topics (diseases) dealt with (differentiation)
- more participants (?)
- more "self help consumers" (!)
- fast growing acceptance in the population
- fast growing acceptance among professionals (in Sunday speeches, at least)
- slowly growing acceptance among professionals (in every day practice and collaboration)
- more support by administrations / politics
- growing influence on the health system (from individual doctor-patient-relation to participation in political / professional decision-making and quality assurance in the health system)
- professionalisation of self help (!) and of self help support (?)
- abuse of self help as a cheap substitute for professional services (!)
- self help under the influence of various "partners" (!) (mind the industries !)

## Participants

<b>Austria</b>	<b>Andrea</b>	<b>Lins</b>	Fonds Gesundes Österreich
		<b>Bach-Evensen</b>	
<b>Austria</b>	<b>Cathrine</b>	<b>Schauf</b>	ArGe Selbsthilfe Österreich
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<b>Greece</b>	<b>Konstantinos</b>	<b>Fradiadakis</b>	Self Help Promoting program
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<b>Israel</b>	<b>Ruth</b>	<b>Belkin</b>	Etza - Israel Self help center
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<b>Lithuania</b>	<b>Violeta</b>	<b>Ivinskiene</b>	Parents in Partnership
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<b>Norway</b>	<b>Frøydis</b>	<b>Eidheim</b>	Frilanser
<b>Norway</b>	<b>Margit</b>	<b>Gyllenhammar</b>	Anxiety Ring Norway
<b>Norway</b>	<b>Solbjørg</b>	<b>Talseth</b>	Norwegian Self Help Forum
<b>Norway</b>	<b>Stein</b>	<b>Bruland</b>	Norwegian Self Help Forum
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			Science Territorial Centre for Social Assistance to
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<b>Sweden</b>	<b>Jannicke</b>	<b>Kihlman</b>	Fenix Sjalvhjalspenter & Frivilligcentral
<b>Switzerland</b>	<b>Vreni</b>	<b>Vogelsanger</b>	Stiftung KOSCH Basel
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